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THE IMPLEMENTATION OF HEALTHY START

LESSONS FOR THE FUTURE

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This report represents one in a series of evaluation reports on the Healthy Start program and should be interpreted in that light. The final report on the national evaluation, which will be completed in fall 1998, will synthesize all previous findings and present findings on key outcome variables including infant mortality rates. An assessment of the ultimate effectiveness of the Healthy Start program will be included in the final report.

CONTENTS

CONTENTS (continued)

CONTENTS (continued)

TABLES

FIGURES

EXECUTIVE SUMMARY

The Healthy Start program was launched in 1991 by the Health Resources and Services Administration (HRSA) of the U.S. Public Health Service to demonstrate innovative ways to reduce infant mortality in some of the areas with the highest infant mortality rates in the country. At that time, the U.S. ranked 22nd in its infant mortality rate compared with other nations, and there were large racial disparities in birth outcomes.

In the fall of 1991, HRSA chose 13 urban areas and 2 rural areas in which to implement a 5-year Healthy Start demonstration of community-based approaches to reducing infant mortality. The goal of the 15 projects was to reduce infant mortality by 50 percent during this period. The demonstration was subsequently extended for one year, and seven additional projects were funded.

HEALTHY START COMPONENTS

Mathematica Policy Research, Inc., and its subcontractors[1] are studying the implementation of the Healthy Start demonstration. All the projects studied have put in place a comprehensive program to address the problem of infant mortality in their respective communities. Although HRSA did not define a specific approach for projects to follow, the results of the planning phase for each demonstration led to substantial similarities. The components of this "Healthy Start program" include:

- Community involvement through a consortium and other community empowerment strategies
- Outreach and case management to identify women, bring them into care, refer them to appropriate services, and track them as they obtain services, generally using lay workers for many functions
- A variety of other nontraditional support services, such as transportation and nutrition education
- Enhanced clinical services, building on an existing delivery system
- Community-wide public information campaigns

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[1]Harvard School of Public Health, Health Systems Research, Inc., and RIVA Market Research, Inc.

ADMINISTERING HEALTHY START

As with any large, complex program, the successful organization and administration of Healthy Start was extremely important. The extent to which projects were able to manage their programs effectively-that is, to develop and implement effective administrative procedures, recruit and retain a strong staff (especially senior staff), and monitor the work of contractors--made the difference between successful and less-than-successful implementation.

As recipients of large federal grants, the projects urgently needed to develop an administrative structure in order to proceed with other aspects of their programs. Most of the grantees (10) were city, county, or state health departments, and the remainder (4) were nonprofit organizations. Being a health department brought several benefits. For example, because the grantees were part of local government, the administrative structures for accounting and data processing did not have to be developed from scratch. Also, health department personnel could be a source of interim project staff These people were often those who prepared the grant proposal, and they could begin project activities and hire and supervise the project director, providing a natural, ongoing, and important link with the project throughout its life. Another primary advantage of the health department as grantee was that it could potentially sustain Healthy Start beyond the federal grant-funding period. Through the influence of health department employees who might maintain contact with or were employed by Healthy Start, program features were more likely to become an integral part of future health department activities, either as fully funded free-standing activities or as parts of existing programs.

On the other hand, a nonprofit organization offered different advantages. Independent of governmental personnel and contracting regulations, nonprofits had more flexibility to quickly develop their Healthy Start program since they were not subject to a time-consuming approval process. Projects with grantees in health departments regretted their lack of administrative flexibility.

The speedy development of a project's administrative structure was facilitated by combining both public and nonprofit administration. Three projects established a nonprofit subsidiary of the city or county government to administer Healthy Start. This arrangement was an appropriate response to-the dual need for flexibility and for close ties with government.

Successful implementation also depended on recruiting and retaining strong senior staff throughout the life of the project. Leading a Healthy Start project, with an annual multi-million dollar budget, proved to be an extremely challenging job, requiring strong administrative ability (including skills in personnel, accounting, and data systems), experience in community relations, political acumen, and a knowledge of programs related to infant mortality. It was also advantageous to select staff who were familiar with the Healthy Start community and of the same racial/ethnic group as the majority of community residents. While it may have been impossible to identify one individual with all of these characteristics, most projects put together a team that had all or most of them.

Much of the work in Healthy Start projects was performed by contractors. We found that, of the $96 million spent by Healthy Start grantees during fiscal year 1996, about 60 percent went to

contractors. Although they performed a wide range of activities for Healthy Start grantees, the most common was the delivery of client services. Consequently, it was essential to establish clear and consistent performance standards for contractors and to be vigilant in monitoring their financial and programmatic performance. Monitoring was an important part of establishing the credibility of a program that paid a large amount of public funds to contractors not under the direct oversight of the federal government. In implementing monitoring protocols, projects encountered internal tensions about how strictly to monitor their operations. This was especially true of projects that used a large number of small community-based providers.

GAINING COMMUNITYINVOLVEMENT ,

Healthy Start was unique in its strong emphasis on community involvement in the original and ongoing federal guidance for the program. All projects took this mandate seriously, but all found it slow, difficult, and challenging, particularly when the grantee was part of a bureaucracy that had to contend with political considerations. Indeed, all observed that involving the community in the program slowed implementation, a concern given the ambitious goal of substantially reducing infant mortality in the relatively short demonstration period.

One community-involvement strategy was mandated by HRSA: the community consortium. This mandate was interpreted very differently from project to project. Some projects did not view the consortium as a critical source of community input or governance, while others treated it as a major component of their intervention. Projects with very active consortia devoted a great deal of energy and time to convening and sustaining these bodies.

Central consortia were generally large groups with a diverse membership made up of providers and community members, including consumers, government representatives, and other concerned individuals. The most active participants in central consortia were providers. Their involvement in the consortia was very useful for developing service networks and beneficial to the project in general. While projects did not establish formal, closed provider networks, they used consortium and committee meetings as a forum in which many different providers could interact, thus increasing the exchange of information and facilitating appropriate referrals.

Providers often influenced the development of the original Healthy Start proposal and, as part of that process, may already have defined their role in service delivery. Other providers may have "come to the table" hoping for a new or expanded role in the project. This financial incentive was one reason for involvement; others included commitment to the health issues involved and to improving systems of care.

Despite the benefits of provider involvement, it created the potential for conflicts of interest. Over time, almost all projects realized the need for guidelines covering conflicts of interest, although these guidelines were applied with varying degrees of strictness. For example, provider consortium members in some projects were excluded from budget deliberations and any decisions about selecting subcontractors to provide services.

While all projects wanted consumers to participate in the consortia, their involvement in the central consortia was weak despite a variety of strategies to draw them in, such as transportation assistance, child care, and adjusting the place and time of meetings. Projects reported that consumers often felt intimidated by the professional composition of consortia and their formal structure and committees.

"Local" consortia emerged as the most promising strategy for addressing this weakness. These smaller, less formal committees met in the community, and the ability to successfully organize them depended on having staff who had experience with and the time for community organizing. But, even in the local consortia, community-based providers receiving Healthy Start funds were often more active than consumers. Still, local consortia were the most promising avenue for consumer involvement in Healthy Start.

Employment strategies, including hiring local residents and contracting with small businesses in the community, broadened community involvement and interest in Healthy Start. While projects found that infant mortality was not a personally compelling issue for most community residents, economic issues were. Consequently, employing residents of Healthy Start communities to deliver some form of services (usually outreach/case management services) was a common way to increase community involvement in all Healthy Start projects. Some projects have played a critical role in job training and job creation in their communities. However, heavy employment of community residents presents both risks and benefits. On the one hand, a large number of residents may be out of work if reduced federal funding for Healthy Start causes cutbacks. On the other hand, the skills developed and work ethic established through employment with Healthy Start could increase residents' potential for employment when demonstration funding ends.

An alternative to directly employing residents as a means of involving the community was to contract with community-based organizations for services, since such organizations were themselves likely to employ community residents. Selecting such providers often was fully or partly delegated to local consortia, giving these groups a substantial and useful role. To the extent that communities developed viable businesses that would continue beyond grant funding, this strategy was potentially more sustainable than direct employment of community residents.

Projects found that a reliance on "grass roots" organizations required substantial technical support from the grantee. For example, small organizations often needed technical assistance to prepare responses to solicitations for proposals or budget revisions. Also, community-based organizations often needed help in developing an administrative structure for payroll, accounting, data collection, and demonstration reporting. In addition, project staff spent a lot of time soliciting and reviewing proposals, awarding contracts, and monitoring performance, since the use of grass roots providers usually resulted in a large number of small contracts spread across many providers.

Finally, political support from community leaders, particularly the top leadership such as the mayor or governor, was very important to successful implementation. A high level of involvement provided some Healthy Start projects with a strong base of support, publicly validating the project and increasing visibility. Political support facilitated networking with other agencies (public and private) and helped garner state and local funding for sustaining Healthy Start activities.

PROVIDING HEALTHY START SERVICES

While Healthy Start was not solely a service delivery demon&ration, about two-thirds of Healthy Start expenditures went to this function. The Minimum Data Set (MDS) client-level data systems showed that about 45,000 clients (pregnant/postpartum women and infants) were served by Healthy Start in fiscal year 1996. The MDS did not provide information on other clients, such as male partners and adolescents who were not parenting but nevertheless received Healthy Start-funded services, although some projects maintained these data independent of the MDS. The demographic characteristics of Healthy Start clients indicate that the program served a group of high-risk women who were disproportionately young, members of minority groups, and of low educational attainment.

Healthy Start projects filled important gaps in services, reaching beyond the traditional scope of clinical care. Three primary types of services were funded by Healthy Start: outreach/case management (O/CM) services, nontraditional support services, and clinical services. O/CM involved activities that identified pregnant/ postpartum clients and brought them into Healthy Start to receive program services, kept them in the program, and referred them to other services as needed. A large proportion (78 percent) of Healthy Start maternal clients received O/CM services. A lay worker model was implemented in most projects and holds great promise for providing services that are accessible and satisfying to mothers served by Healthy Start. This model appeared to work best when it (1) was implemented by teams in which the ratio of lay workers to professional workers was relatively low, (2) incorporated intensive and ongoing training and mentoring, and (3) included relatively low caseloads, especially for the lay workers.

The wide range of nontraditional support services provided by Healthy Start included transportation, child care, and nutrition education. Over 50 percent of Healthy Start clients received one or more of these services funded by the program.

Finally, Healthy Start funded clinical services. The projects evolved within an existing service delivery environment. Particularly in the urban settings, projects identified modifications to and coordination of existing services as the greater need compared with creating new services. Expansions and modifications included adding child care or play areas, adding critically needed staff, improving appointment tracking, and expanding hours. Unfortunately, the MDS does not provide a complete count of women and infants who received such services.

Focus groups of clients and providers provided positive feedback about Healthy Start services. Clients especially liked the caring and accessible services they received from Healthy Start. Providers appreciated the coordination function of Healthy Start, making it easier for them to work together to improve the delivery system.

Many projects began delivering services-or contracting for those services-before they had clearly articulated why they wanted to deliver them, what they wanted to accomplish by doing so, and how the services related to infant mortality. This made it more difficult to establish interim objectives that could be used to measure progress. A clearer definition of service delivery models early in the project would have facilitated the development of service delivery protocols, which, in

turn, would have made it easier to monitor contractors and the consistency of service delivery across multiple sites.

OTHER IMPORTANT COMPONENTS

The following components of Healthy Start have not generally been part of other initiatives to reduce infant mortality:

- ***Public Information.*** At the national and project level, Healthy Start funded public information campaigns that used a variety of media (television, radio, and print media such as billboards and brochures) and other strategies to communicate with the public. The purpose of these activities was to inform the public about Healthy Start and to communicate more general health education messages oriented toward reducing infant mortality. We found these creative strategies to be an important and innovative part of Healthy Start.

- ***Management Information Systems.*** Projects were required to develop management information systems in order to provide data for the national evaluation; some used the funding to develop a broader system that could be used for other purposes, such as coordinating services across providers. The projects worked hard to collect evaluation data through their MDS systems, but no project succeeded in collecting a complete data set for any period. However, projects did collect and report some data, demonstrating that community-based projects such as Healthy Start can collect client-level data. The demonstration showed that the data set should be small (much smaller than the MDS) and that clearer instructions and data definitions should be provided early in the demonstration period.

- ***Local Evaluation.*** All 14 projects covered in this report used some of their funds to conduct their own local evaluations. Most were conducted by local university faculty, who have produced numerous reports on a variety of subjects. HRSA ***Guidance*** suggested that the local evaluations should be process-oriented and should not overlap with the activities of the national evaluation.

- ***Infant Mortality Review.*** All projects implemented a review program in which infant deaths in the project area were reviewed by local committees in order to recommend ways to prevent future infant deaths. The programs were appreciated by project staff and consortium members as an important source of local information on infant mortality. However, such programs were costly and some components, such as the maternal interview, were difficult to sustain.

NEXT STEPS IN THE NATIONAL EVALUATION

Healthy Start has shown that local communities can, with substantial federal funding, develop and implement innovative approaches to reducing infant mortality. Since Healthy Start projects, for the most part, implemented a nontraditional service model, the linkage between such services and infant mortality was often unclear and untested. Healthy Start, as designed and implemented, is a long-term rather than a short-term strategy for reducing infant mortality. It is possible that the impact of the demonstration on infant mortality will not be observed in the relatively short period of the national evaluation. Future reports from the national evaluation will address the issue of whether these programs have, as yet, led to measurable reductions in infant mortality in the Healthy Start communities.

I. INTRODUCTION

Infant death is more common in the United States than in most other industrialized countries. With a mortality rate of 8.5 deaths per 1,000 live births in 1992, the nation ranked 22" in the world (U.S. Public Health Service 1996). In response to this situation, the Health Resources and Services Administration (HRSA) sponsored Healthy Start, a demonstration program intended to reduce infant mortality by 50 percent within 5 years through community-based activities. To assess the effect of these interventions on infant mortality and maternal and infant health, HRSA contracted with Mathematica Policy Research (MPR) and its subcontractors, the Harvard School of Public Health, Health Systems Research, and RIVA Market Research, to conduct a five-year evaluation of the Healthy Start demonstration. [1]

This report describes and compares the implementation of the demonstrations in 14 communities, providing insights into approaches to developing such programs in other parts of the country and into problems that may arise in the process. The report is thus expected to be of interest to policymakers and providers seeking to implement similar broad-based community initiatives.

This introductory chapter explains the demonstration funding and site selection process and summarizes the design of the national evaluation. Chapter II presents a general description of the Healthy Start program; Chapter III describes the organization, management, and staffing structures in the demonstration areas as well as the Healthy Start consortia and other community involvement

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'The demonstration was subsequently extended for one year in order to give a full operational period, since implementation was slower than anticipated. Seven new "special projects" were also added: Dallas; Milwaukee; Mississippi Delta; Newark, New Jersey; Panhandle, Florida; Richmond; and Savannah. These projects were funded at approximately $1 million per year each for 2 years. This report addresses implementation for 14 of the initial 15 projects. The implementation of the Northern Plains project, spread over several states and 19 sites, will be described in a separate report to address its unique program design in more depth. The 7 new projects will not be addressed by the national evaluation.

strategies used by the grantees. Chapters IV and V discuss the Healthy Start program interventions, including strategies for improving both access to services and the quality of prenatal and infant care, and for implementing a variety of other behavioral and social interventions. Chapter VI discusses the prospects for sustaining Healthy Start beyond federal funding. Chapter VII presents some conclusions and key lessons from the implementation of Healthy Start.

A. PROGRAM BACKGROUND

Initially proposed by the Bush Administration, Healthy Start, from its inception, emphasized changing whole systems of care. Through Healthy Start, HRSA sought to demonstrate whether communities with high rates of infant mortality could-with substantial planning and funding, as well as strong political and program support at all levels-develop programs that reduce infant mortality and respond to the unique social and health care needs of their residents. Under the leadership of HRSA and with strong support and advice from the Secretary's Advisory Committee on Infant Mortality, the Administration issued the Guidance *for the Healthy Start Program (U.S.* DHHS 1991). As stated in the *Guidance,* "The sites will utilize a community-based, family-centered, and culturally competent approach that will strengthen the maternal and infant care system and bring child-bearing-aged women, pregnant women, and infants into care early, maintain them in care, and assist families in changing their community and home environments to be more conducive to a healthy start for infants."

The program has developed congressional support since the time it was initially proposed. In 1996, Congress appropriated funds to continue the existing Healthy Start projects for a sixth year, one year beyond the original five year time frame. Additional funds have been approved for the original projects a seventh year, during which time existing projects will be funded at a reduced level to continue with one or more of nine program "models." Forty new projects have been funded to initiate programs that build on the lessons learned from the existing projects.

The original ***Guidance*** outlined the grant application process and the fundamental framework for the projects. The following five principles were described as the cornerstone of the Healthy Start approach to service planning and development: innovation, community commitment and involvement, increased access, service integration, and personal responsibility. Applications were submitted in July 199 1 for funding in September of that year.

To be eligible, a project area had to have an average annual infant mortality rate of 15.7 deaths or more per 1,000 live births, a rate more than 50 percent of the national average based on official vital statistics for the 5-year period 1984-88. Areas also had to have at least 50, but no more than 200, infant deaths per year. In addition, applicants had to be local or state health departments, other publicly supported provider organizations, tribal organizations, private nonprofit organizations, or consortia of the same if approved by the chief elected official of the city or county, by the governor of that state, or by tribal leadership. The initial demonstration period was five years, with the first year primarily devoted to developing a "comprehensive plan." Continued funding for the demonstration depended on HRSA's approval of this plan. Numerous communities around the country developed proposals for Healthy Start grants. Forty proposals were submitted, and 2 1 were approved for funding. In September 1991, 15 communities were selected to receive planning grants.

To give communities the flexibility to use local resources and address local issues, the federal government established broad goals and criteria for the Healthy Start grantees. The following were required of all grantees:

- ***Focus on Reducing Infant Mortality. Grantees*** were given the goal of reducing infant mortality by 50 percent over five years.
- ***Include the Community in Planning.*** Grantees were to organize a Healthy Start consortium that would determine and coordinate local efforts to reduce infant mortality.

- ***Assess Local Needs.*** Grantees were to have a process for identifying both the services needed in their community and the key characteristics of the environment in which services would be provided.

- ***Increase Public Awareness.*** Each grantee was required to develop a public information component that would "focus on developing awareness and support for the initiative and sensitize the larger community to the issues relating to infant mortality."

- ***Implement an Infant Mortality Review (ZMR).*** Grantees were encouraged to develop procedures for reviewing all infant deaths in the project area and to disseminate that information to the consortium for their use in program planning.

- ***Develop a Package of Innovative Health and Social Services for Pregnant Women and Infants. The*** content of the service package was not specified, although a long list of possible interventions was suggested.

- ***Evaluate the Initiative.*** Grantees were to monitor their progress toward goals and cooperate with a national evaluation. Additional local evaluation activities could complement the national evaluation at the grantee's option.

During the initial years of the Healthy Start program, implementation was shaped by federal, state, and local circumstances. At the federal level, the appropriated funding for the program was substantially less than initially proposed (although it has continued beyond the initial five-year period), and the number of grantees was greater. Therefore, the budget for operation was less than most projects anticipated during the comprehensive planning process. Healthy Start was initially administered by HRSA's Office of Planning, Evaluation and Legislation (OPEL), using staff from the perinatal units of operational bureaus. OPEL also had lead responsibility for the process development of the evaluation design (under contract with Lewin/VHI) and oversaw the Healthy Start National Evaluation. The Healthy Start staff office was moved to the Maternal and Child Health Bureau of HRSA in 1993, establishing a more permanent structure for admiistering the program and providing ongoing oversight and technical assistance for grantees. At the local level, implementation varied by community, influenced by its own planned approach and often unexpected political, administrative, and logistical factors.

B. THE HEALTHY START PROJECTS

The 14 Healthy Start projects covered in this report include Baltimore, Birmingham, Boston, Chicago, Cleveland, Detroit, the District of Columbia, New Orleans, New York City, Oakland, Philadelphia, Pittsburgh, Northwest Indiana, and the Pee Dee region of South Carolina. Northwest Indiana is a cluster of four smaller cities within Lake County, Indiana (Gary, Hammond, East Chicago, and Lake Station). Pee Dee includes six rural counties. While the projects differ greatly from one another in terms of their geographic, cultural and political environment, they have a great deal in common. All are poor communities with a high proportion of minority residents. As shown in Table I. 1, in 1990 all had a relatively large population of African Americans (from 43.7 percent in Pittsburgh to 95.0 percent in Baltimore), and some had significantly large Latino populations (Boston, Chicago, New York City, Northwest Indiana, and Oakland). Educational attainment levels in Healthy Start areas was also quite low, with more than 30 percent of adults having less than a high school education in each area.

The project areas also had a high rate of infant mortality. As shown in Table I. 1, the infant mortality rate in the 1989-91 immediate predemonstration period in Healthy Start communities ranged from 9.8 (Boston) to 24.9 (Detroit) per 1,000 live births. The national rate was 9.0 per 1,000 live births in the same period.

Although not shown in the table, the Healthy Start areas are plagued by a variety of poverty-related problems such as elevated unemployment rates, community and domestic violence, substance abuse, poor housing, homelessness, and health conditions such as HIV, tuberculosis, and many others. Infant mortality is only one part of a large and complex constellation of social and health problems in these communities.

TABLE I. 1

PROJECT AREA CHARACTERISTICS

Projects	Population, 1990' Total	Percent African American	Percent Latino	Percent of Adults with < H.S. Education	Infant Mortality Rate 1989-91[b]
Baltimore	49,147	95.0	0.6	54.7	15.8
Birmingham	182,788	81.5	0.3	36.9	19.6
Boston	283,167	47.4	14.7	31.0	9.8
Chicago	221,688	54.7	26.9	48.1	19.8
Cleveland	248,038	85.1	1.9	42.6	17.2
Detroit	456,108	91.3	0.6	42.4	24.9
DC	141,062	94.0	1.1	37.1	23.5
New Orleans	174,282	87.0	2.6	47.8	17.4
New York	478,211	71.0	24.7	N/A	18.5
N.W. Indiana	248,673	45.5	13.9	34.6	12.0
Oakland	175,487	53.9	18.8	37.1	12.4
Pee Dee	229,617	46.5	0.3	43.9	15.8
Philadelphia	301,699	68.8	1.3	34.7	15.2
Pittsburgh	225,529	43.7	0.8	31.3	17.4
U.S.	**248,710,000**	**12.1**	**9.0**	**24.8**	**9.0**

'Project areas are defined by census tract, zip code, or county. Data come from the 1990 U.S. Census using Atlas Select software for small areas. For New York City, data come from the project's comprehensive plan, updated throw personal communication with project staff. U.S. data come from the ***Statistical Abstract of the U.S: 1993.***

[b]Data come from state linked birth-death files. Data for Baltimore, Boston, and DC are for 1990 and 1991 only. Data for the U.S. come from the National Center for Health Statistics (U.S. DHHS 1996).

C. THE NATIONAL HEALTHY START EVALUATION

The national cross-site Healthy Start evaluation includes an outcome analysis and a process analysis.[2] The outcome analysis assesses whether Healthy Start achieved its goal of reducing infant mortality by 50 percent over 5 years and uses secondary data sets, including linked birth/death certificates. In contrast, the primary goal of the process analysis, of which the current report is a part, is to develop an understanding of each Healthy Start project--its interventions, how they were implemented, and barriers to implementation. This information will be used as context for interpreting the outcome analysis results and for assessing the extent to which Healthy Start can guide other communities with high rates of infant mortality.

The secondary goal of the process analysis is to identify indicators of the success of Healthy Start that may not become evident from the outcomes analysis. For example, Healthy Start services may have created a more integrated system of prenatal and pediatric services in a community even if they had no clear impact on infant mortality rates.. Given the short-term nature of the Healthy Start demonstration, lessons such as these may be extremely important to the nation's future efforts to improve maternal and child health.

Projects were nearly two years into developing their programs when the contract for the national evaluation was awarded (October 1993). It was therefore important to assess as soon as possible the issues associated with implementing Healthy Start in its first two years in order to preserve the early implementation experience. Consequently, visits to all projects were conducted in January-April 1994.[3] In subsequent years, the process analysis collected information from follow-up telephone calls

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[2]For additional detail on the design of the national outcome and process evaluation, see Devaney and McCormick (1993) and Raykovich et al. (1996). Local evaluations, conducted by most Healthy Start projects, are primarily process-oriented and designed to assist each grantee in monitoring its program operations.

[3]See Howell et al. (1994) for the results of those visits.

in April 1995, a second round of site visits in January-February 1996, and a final round of telephone calls in May-June 1997. As part of the second round of site visits, focus groups with clients and providers provided more in-depth qualitative information on the projects. For all site visits, telephone calls, and focus groups, semi-structured protocols ensured that the information gathered across projects was comparable.[4] This information falls into the following categories:

- Project ***Structure:*** staff roles, recruitment, training, retention, and reporting relationships; and processes for contracting and providing technical assistance
- ***Community Context:*** demographics, politics, major community health problems, sources of medical care and key providers, Healthy Start efforts to improve access to care, and changes in the Medicaid program
- ***Consortium:*** previous efforts to reduce infant mortality, adequacy of representation from key segments of the community, structure and reporting relationships, role in setting project goals and objectives, authority for key decisions and policies, role of project staff, controversial issues and how they were resolved, role of local or sub-area consortia, major strengths and weaknesses
- ***Public Information: types*** of activities, estimates of penetration
- ***Outreach and Case Management: types*** of services and agencies providing them, the case management process for a typical client, eligibility, experience and training of individuals providing services, how staff are recruited and retained, and monitoring of case management quality and operations
- ***Service Delivery***: a complete list of service providers both funded by Healthy Start and available in the community, and methods by which providers become part of the Healthy Start network and coordinate their services with other providers

In addition to information gathered in site visits, two other sources provided data for the process analysis. At the end of program year five-fiscal year 1996 (October 1995 to September 1996)--projects completed an expenditure report according to certain predefined categories of expenditures.

[4]The initial site visit protocol is included in Howell et al. (1994). Similar site visit and telephone update protocols were used to collect subsequent information. The protocol for the focus groups is included in Devaney et al. (1996).

Each site's client-level data set, known as the Minimum Data Set (MDS), was obtained for fiscal year 1996 for all projects.[5]

To summarize and synthesize the wealth of information obtained from these various sources, the site visitors met to identify the broader themes emerging from their interviews, and to characterize the success of implementation of the various program elements in each project. In addition, a conceptual approach to classifying different approaches to program implementation was developed. This framework was used to present the cross-site analysis provided in this report.

In order to evaluate how projects were performing on certain dimensions of administrative success, projects were scored by site visitors on a scale of one (low or poor) to seven (high or good), with four being a neutral score. These rankings were developed through a modified-Delphi consensus process by all the site visitors (generally four) to each site; visitors assigned scores independently and then met to discuss and resolve differences. Some of these scales are presented in this report beginning on page 26. However, individual projects are not identified in the charts displaying this information. Rather, projects are arrayed on each dimension from highest to lowest in order to show the variability in the particular dimension. Thus, a project may be displayed as high on one dimension but low on another dimension.

Another data set used in the national evaluation is a postpartum survey of Healthy Start clients and other postpartum women in the project areas. Those data will be analyzed in the near future, and results will be presented in a separate report.

[5]To ensure comparability with the expenditure data, we included fiscal year 1996 MDS data in this report; while we have obtained data for earlier years, this information is substantially incomplete for most projects.

II. THE HEALTHY START PROGRAM

The Healthy Start projects have emerged within local political and service delivery environments that include other programs intended to improve birth outcomes. Three important aspects distinguish Healthy Start from these other initiatives: (1) size and scope, (2) emphasis on community involvement, and (3) locally designed interventions. As a result, each of the 14 Healthy Start projects has designed its own interventions responding to its own unique needs, with varying amounts of funds devoted to each program component. This chapter describes the Healthy Start program, including an overview of the models implemented by each project and a discussion of grant size and program expenditures.

A. PROGRAM SUMMARIES

Healthy Start projects were given the flexibility and encouragement to develop diverse programs. Within the very broad requirements outlined in Chapter I, the projects had only to tie their efforts to the broad goal of reducing infant mortality. This led to programs that, in contrast to traditional prenatal and infant care programs, had the following features:

- An outreach component designed to find and engage women in the program, often through home visits, and to remain in contact with them throughout pregnancy and their child's infancy
- A network of support services beyond traditional care services including, for example, education, transportation, housing, employment assistance, translation services, and mental health and substance abuse counseling
- Delivery of services by local residents

Because Healthy Start communities had an array of services for pregnant women and infants that predated the program, projects had a base on which to add new components or to enhance existing services. They also adopted a range of interventions to enhance access to these services.

The service components of Healthy Start fell into three categories: outreach and case management (O/CM), support services, and clinic enhancements. All projects implemented some form of outreach and case management to improve the coordination of care for women and infants. Support services such as child care, transportation, health education, and substance-abuse counseling and treatment were offered in varying combinations across projects depending on the needs of the individual communities. These services were intended to enhance and improve access to care. Clinic enhancements, such as extended hours, additional providers, and improved facilities and equipment were intended to improve both access to and quality of care.

The nonservice components of Healthy Start were intended to improve management of the program, to build an understanding of what worked well, and to reveal the remaining shortcomings in Healthy Start and the larger service delivery system. These components include the consortium, management information system, infant mortality review, and local evaluation. In addition, all projects implemented public information/media activities to publicize Healthy Start and educate the larger community about infant mortality and related issues. A federal public information campaign complemented the local activities. The capsules that begin on the next page exemplify the variety and individuality of these 14 Healthy Start program models. Appendix A shows individual timelines for each project and Appendix B shows maps of the Healthy Start service areas.

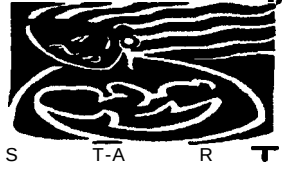
BALTIMORE CITY Healthy Start
Healthy Babies Healthy Families

BALTIMORE. The Baltimore Healthy Start project focuses its intensive model of service delivery in two neighborhoods within the City of Baltimore. In each of these two target areas, the project has established Neighborhood Healthy Start Centers (NHSCs) which serve as the focal point for service delivery to Healthy Start clients. NHSCs offer intensive outreach and home-based case management services, as well as a range of center-based health education, patenting education, addiction counseling, support groups, life planning, and men's services. Other project components covering broader areas of the city include maternal and infant nursing, in which teams of public health nurses conduct home visits to high-risk mothers and infants, and a medical reform initiative through which 18 prenatal, pediatric, and family planning providers are receiving funding to achieve a range of specific objectives, including improving facility conditions, decreasing waiting times, bolstering health education and related services, and facilitating male involvement.

The project is advised by a central project consortium and two local consortia. The Baltimore Healthy Start project is administered through a 501(c)(3) private, non-profit, quasi-public corporation, Healthy Start, Inc., which works with the grantee, the Baltimore City Health Department, to oversee day-to-day project management.

BOSTON. The Boston Healthy Start Initiative provides services through a network of over 70 community-based agencies, including Neighbor-hood Health Centers, tenant organizations, non-profit community groups, and shelters. This model builds upon and takes advantage of Boston's rich network of community-based providers, offering additional funding to these agencies to enhance and coordinate their services. All services are provided through contracts. A diverse set of services is funded, each falling into 1 of the following 22 categories: adult education, career development, case management, community organizing and mobilization, diversity training, domestic violence intervention, domestic violence training, ESL and GED, health center capacity building of ancillary services, improving social conditions of pregnant women, infant health care, neighborhood empowerment, nutritional support, outreach to nonclinical sites, perinatal substance abuse, pregnancy and parenting support, smoking cessation, systems interventions, teen leadership, transportation and childcare, women's health education and youth outreach.

Oversight is provided by a large central consortium *with* extensive community involvement. A 30-member Executive Committee selected from the full consortium is responsible for policy and program oversight, and six committees conduct the substantive work of the Executive Committee.



BIRMINGHAM. The cornerstone of the Birmingham Healthy Start project is the Healthy Start service delivery centers, which offer health education, family planning, and child care services and provide a base for outreach services. Although at one time the project was operating 11 centers, these have now been reduced to four. Contracted services, which may or may not be directly linked to the Healthy Start service delivery centers, include adolescent pregnancy prevention classes, peer counseling, support services, male involvement and counseling, residential substance abuse treatment, and transportation.

While the Birmingham Consortium was originally intended to serve in an advisory capacity to the Birmingham Health Department, the project grantee, which is fully responsible for budget, policy, and program decisions, it *now* serves primarily as a forum for information-sharing and education of consortium members. Load consortia were originally formed, but these have become inactive over time.

CHICAGO. The Chicago Healthy Start project focuses on case management and the coordination of services through Healthy Start Family Centers. The Family Centers are "one-stop" facilities where all major services are integrated and enhanced. These services include intensive case management, prenatal care, pediatric care, general primary care, health education, nutrition, counseling, and substance abuse treatment. As a part of Healthy Start, the Family Centers also were one of the first to offer the Healthy Families America program, which provides m intense home visiting intervention to prevent child abuse md neglect.

CLEVELAND. The Cleveland project, called Healthy Family/Healthy Start (HF/HS), focuses on the provision of outreach and case management services. These services arc provided through one major contractor, the Neighborhood Centers Association, a metropolitan-wide organization that plans, coordinates, and budgets neighborhood center work. The outreach and case management services are provided throughout the service area by eleven neighborhood settlement houses, using lay, indigenous outreach workers, community organizers, and social workers. Risk assessment tools developed by HF/HS determine the level and frequency of the intervention.

The project is overseen by an executive council made up of members of the consortium. The council includes participants, outreach workers, medical and social service providers, administrators, health care organizations, as well as representatives from Ohio's Title V office, county government officials, and the mayor's office.

DISTRICT OF COLUMBIA. The DC Healthy Start project focuses- on three major service delivery components: case management, provided in clients' homes by nurse case managers and lay Resource Parents; outreach and social support, through which health educators and outreach workers provide health education and work to identify potential clients for the case management services; and perinatal health, which provides funding to providers in the service area to expand their hours, improve their facilities, and hire additional skilled staff, including obstetricians, nurse practitioners, and pediatricians.

The consortium structure in the DC project includes several levels of community involvement. The consortium as a whole provides a forum for project staff and work group members to report to the community on their progress; the consortium's six work groups address programmatic issues relating to the project; and the consortium's steering committee serves as an advisor to the DC Office of Maternal and Child Health, the grantee agency, reviewing program, staffing, budgetary, and policy issues.

DETROIT. The Detroit Healthy Start model includes four major components Direct client services are provided by outreach and case management teams in each of three regions, as well as a Public Health Support Services team, which consists of social workers with special training in HIV/AIDS, substance abuse, and domestic violence, as well as a health educator, a nutritionist, and a male responsibility specialist. The PHSS team provides education and direct support and counseling services to women throughout the project area upon referral from the outreach teams. Additionally, the Detroit project supports enhancements to local clinical services, including funding for additional staff at local hospitals, and Community Development Initiatives, which consist of grants to smaller, grassroots organizations in the project area to conduct services such as counseling for teen parents and home-based services to pregnant women with developmental disabilities.

The Detroit consortium is a largely advisory body. There are also local advisory councils. Responsibility for project administration and budget and policy decisions is divided between two grantee agencies: the prime contractor is the Detroit Health Department, and their major subcontractor is the Department of Community Medicine at Wayne State University.

NEW ORLEANS. The New Orleans Healthy Start project called Great Expectations, covers ten service areas throughout the city. In each service area, a local agency conducts outreach and case management activities, managed by one project-wide contractor. Outreach and case management services are based on the traditional community concept of godparents, known as Nanans and Pat-rains. These lay outreach workers and case managers are overseen by professional social workers. In addition to outreach and case management, the project has enhanced the clinical services provided through five community clinics by providing funding for additional staff and ancillary services. The project also funds substance abuse treatment services and educational and health services for adolescents.

The project's central consortium includes providers, health care organizations, and community members; the consortium elects members to a steering committee and a leadership council, and maintains six working committees. The central consortium's role is primarily an advisory one and a liaison to the community, although the recommendations of the committees are used in making funding decisions. Each of the ten service areas also has an Advisory Council that includes substantial community. representation; these also assure that the community has a voice in the direction of the program. The chair of each of these local councils serves on the central consortium's Steering Committee, providing a link to the local community.

NEW YORK. The New York Healthy Start project covers three distinct service areas in three boroughs of New York City-Central Harlem in Manhattan, Mott Haven in the Bronx, and Bedford in Brooklyn. Each service area has one agency that serves as a main contractor to the grantee and in turn subcontracts to individual service providers. These subcontracts focus on strengthening the perinatal service delivery system; recruiting; and training midlevel practitioners; linking high-risk pregnant and parenting women and infants with outreach and intensive case management services; and providing consumer training, specialized adolescent and peer support services, and health education.

The project is overseen by a project-wide consortium consisting of approximately 100 members; the central consortium serves as a forum for information exchange between the project, which is administered by Medical and Health Research Associates of New York City, Inc. (MHRA), and the community. The consortium elects a management and governance committee to provide more direct project oversight of policy and budget issues. Four additional subcommittees address specific programmatic areas. In addition, each of the three service areas has a local consortium in which community-based agencies and consumers are active participants.

OAKLAND. The Oakland Healthy Start (OHS) project area includes 49 census tracts, with project activities targeted specifically to three key communities: West Oakland, East Oakland, and Fruitvale/San Antonio. The main intervention of the Oakland Healthy Start model is the establishment of three "one-stop shopping"-model Family Life Resource Centers (FLRCs) in each of the project's three target areas. The FLRCs are charged with providing services in six major areas: health promotion, case management, family empowerment, outreach, manhood/womanhood youth development, community revitalization, and economic development. Oakland Healthy Start has also awarded contracts to other community agencies to increase the availability of needed services, to provide direct support to the FLRCs, and to conduct evaluation, public information, and other project activities.

The OHS consortium structure has continued to evolve over the course of the project, initially building on the existing Oversight Conunittee on Infant Mortality, and later developing an Advisory Board to oversee Healthy Start specifically. As with other projects, the primary difficulty has been engaging a sufficient level of participation by community residents.

NORTHWEST INDIANA. The project area for Northwest Indiana Healthy Start covers four jurisdictions: Gary, East Chicago, Hammond and Lake Station. The project has established "one-stop shopping" centers in each of the four cities (two in Gary and one in each of the other three cities); these provide services tanging from clinical prenatal, postpartum, and infant care to support services such as case management, health education, and WIC services. Because of a severe lack of clinical services in many areas, the project has also focused on enhancing clinical services through the establishment of new clinics and expanding hours in existing sites.

The project's consortium is made up primarily of traditional providers and representatives of government agencies; few community members or representatives of community-based agencies participate. The consortium has four planning committees as well as a governing board (made up of the four cities' mayors), and a managing board (made up of the four health directors). The consortium itself is seen mainly as a vehicle for information-sharing, while the business of overseeing the project, including approval of budgets, is done by the governing and managing boards. In addition to the central consortium, local planning committees in each of the four cities oversee project activities in their communities.

PEE DEE. The Pee Dee Healthy Start project area includes six counties in the Pee Dee region. The model therefore provides a range of services in each of these six counties, including Rural Outreach, Advocacy, and Direct Services (ROADS) teems, which provide outreach, case management, health education, alcohol and drug counseling, and limited clinical services at sites throughout each county; Teen Life Centers in each county, which provide counseling, support services, and health education for adolescent men and women; Nurturing Centers, which provide family support services to families at risk of child abuse; and school health services. In addition to these services, the project has funded provider recruitment and clinic enhancement efforts, and funds Interfaith Initiatives, which provide small grants to church groups to provide education, self-esteem, and parenting classes.

Because of the geographic dispersion of the Pee Dee Healthy Start efforts, much responsibility for program development and budget decisions has, over time, been delegated to local consortia, known as County Coalitions, in each of the six project counties. Each of these local consortia is represented in the Regional Council, which provides more general project oversight.

PHILADELPHIA. The Philadelphia model is based on the provision of services through contracts with 65 community agencies to provide services in five major categories: lay home visiting (provided in three of the project area's eight census tracts), outreach (to identify potential clients in these three census tracts), enhancement of clinical services (including hiring nutritionists, social workers, and support staff), community education (including peer counseling programs, breastfeeding education programs, and SIDS support groups), and community support (focusing on non-clinical services in medical settings, such as in-clinic child care and social work follow-up in hospitals). All services are provided through contractors, except for some outreach conducted by grantee staff.

The project's central consortium serves in an advisory capacity to the project grantee, the Philadelphia Department of Public Health. Subgroups of the consortium include a steering committee and five workgroups. The project has no local consortia

PITTSBURGH. The Pittsburgh Healthy Start project area is divided into six distinct regions, with all services delivered on the regional level. The primary services included in Pittsburgh's model are outreach and case management, provided by one contractor through Core Teams in all six regions, and family planning, with educational and clinical services offered within each neighborhood by a single contractor. In addition, the project's Specialty Contracts provide funding for community-based agencies to provide a range of services based on the needs of their regions, including job counseling and training, family support services, basic education, and programs for youth.

The primary responsibility for project oversight lies with the grantee, the Allegheny County Health Department, while program implementation and administrative functions lie with the Board of Directors of Healthy Start, Inc. A great deal of responsibility for program development and funding decisions is also held by the local consortia that have been established in each of the six regions. Each of these consortia, in addition to making funding recommendations for specialty contracts in their regions, is represented on the Healthy Start, Inc. Board.

B. PROGRAM EXPENDITURES

Although Healthy Start was initially implemented as a five-year demonstration program, significant funding was approved to continue the program for a sixth year, as shown in Table II. 1. Almost $403 million in initial grants were awarded to the 14 projects for fiscal years 1992-1997. Congressional support for Healthy Start remains high, with $96 million appropriated for fiscal year 1998 to continue the more successful components of existing projects and fund 40 new projects. Table II.1 shows the initial grant awards by project for the first six years of Healthy Start, including the initial planning year in fiscal year 1992. In addition to these initial grant awards, more funds were often released to projects during the year. In general, the "smaller" programs, as defined by the size of grant awards, are those that had implementation difficulties at some time in their history that caused delays in spending or restrictions in grant awards from HRSA.

TABLE II. 1

HEALTHY START INITIAL GRANT AWARDS BY YEAR AND PROJECT
(In Thousands)

	Grant Awards							
	Planning Year	Operations						Expenditures
Project	PY92	FY93	FY94	FY95	FY96	FY97	Total	FY96
Baltimore	1,657	4,647	6,544	7,439	8,361	7,856	36,504	10,204
Birmingham	1,744	3,845	1,972	4,101	2,136	2,676	16,474	4,230
Boston	1,871	4,202	6,473	6,547	7,920	6,495	33,508	8,167
Chicago	1,584	4,442	6,671	7,665	8,010	6,731	35,103	9,105
Cleveland	1,538	3,608	4,509	6,523	7,429	6,440	30,047	5,847
Detroit	1,870	4,297	4,182	2,483	4,312	2,769	19,913	4,653
DC	1,855	3,827	5,493	7,197	5,080	5,997	29,449	6,076
New Orleans	1,246	3,209	5,443	7,197	8,965	3,379	29,439	8,244
New York	1,871	5,437	6,500	7,715	8,464	7,038	3 7,025	7,849
N.W. Indiana	284	2,796	4,087	3,696	4,776	5,526	21,165	4,707
Oakland	1,871	3,460	5,090	6,221	7,735	3,628	28,005	6,470
Pee Dee	1,213	3,921	6,356	6,496	2,012	2,030	24,040	6,154
Philadelphia	1,857	4,457	5,753	6,229	7,326	7,361	32,983	7,557
Pittsburgh	1,844	4.653	5,176	5,070	6,240	6,183	29, I66	7.113
Total	22,305	56,801	74,249	84,579	88,766	74,109	402,821	96,376

NOTES: These amounts represent initial grant awards for each years; additional funds were released to some grantees in some fiscal years. The planning grant for each project, with the exception of Northwest Indiana, included funding for the first three months of program operation. The Northwest Indiana project did not elect to begin program operation during its initial grant year.

The aggregate grant awards can give only a general impression of the size and scope of the Healthy Start effort because they do not show how the projects actually spent their funds. Table II. 1 shows grant awards at the beginning of each fiscal year and consequently does not take into account the funds that are sometimes released during the year. In addition, projects do not always spend their full award and are sometimes allowed to "carry over" some portion of unspent funds into the next year. Consequently, the annual award amounts are not always an accurate representation of the actual program expenditures in a given year, but the total over the full seven years of the program is a close approximation of each project's total expenditures.

The final **column** of Table II. 1 shows actual fiscal year 1996 expenditures for Healthy Start for the 14 projects. This column was prepared using data from a special expenditure report. To obtain a more detailed view of the distribution of expenditures across various activities, we requested this special report for fiscal year 1996. Such a report was not a routine part of Healthy Start reporting, **and it** would have been extremely difficult for projects to prepare the report retrospectively for all program years.

The 14 projects spent approximately $96 million in fiscal year 1996. These expenditures, either direct or contracted, fell into the following categories, which were defined uniformly for all projects:

- ***Administration/Consortium Development. The*** administration/consortium development category includes funds for staff positions and nonlabor expenditures that facilitate **the** provision of services, but that do not provide direct services to Healthy Start clients. For example, administrative funding covers costs associated with program management, accounting, human resources, clerical operations, staff training, and building maintenance and security. The costs of consortium operations are also assigned to this category because they are very difficult to separate from administrative costs. These costs include expenditures for developing the consortium, cultivating consortium membership, **and organizing and attending consortium and committee meetings.**

- ***Service Delivery.*** Service delivery includes all funds for staff positions and nonlabor expenditures intended to provide services directly to Healthy Start clients. Direct

service is broadly interpreted to entail personal contact between a Healthy Start staff member and one or more clients. The personal contact need not be face-to-face; telephone-based case management, for example, should be considered a direct service.

- ***Other Expenditures, Such as Public Information, Management Information Systems (MIS), Local Evaluation, and Infant Mortality Review (IMR). These*** expenditures include costs for initiatives tbat are aimed at the entire community within the target area rather than at Healthy Start clients only.

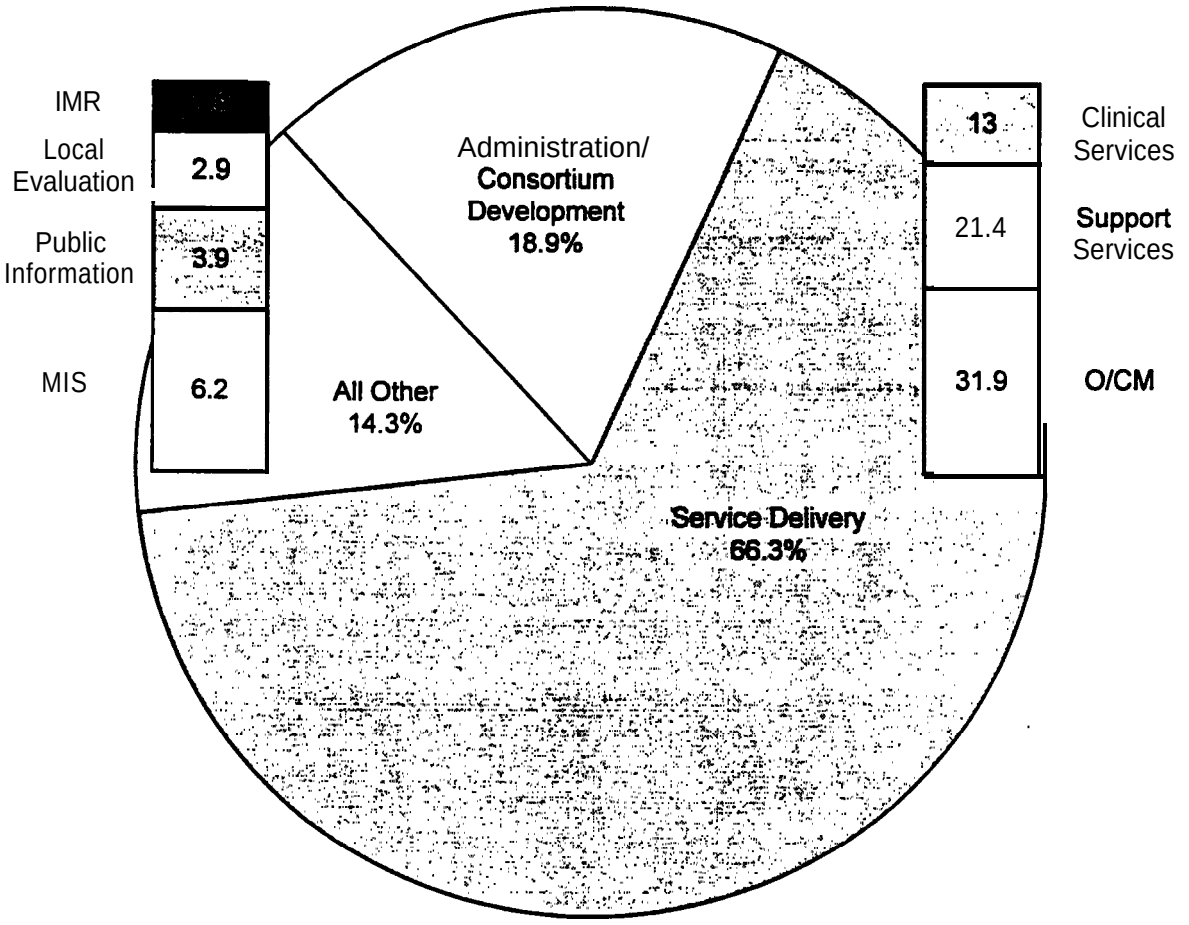
Figure II. 1 illustrates how program expenditures were distributed across categories for the ***14*** projects combined. About 20 percent of total Healthy Start expenditures (or about **$** 18 million) for these 14 projects went to administration and consortium development; about 65 percent went to delivery of services; and the remainder went to other categories including public information, MIS, local evaluation, and IMR.

Since Healthy Start has adopted an innovative approach to reducing infant mortality that does not rely only on service delivery, it is important to carve out other special expenditures unique to Healthy Start-such as consortium development, public information, infant mortality review, and other **forms** of data collection and evaluation. Our analysis shows that about a third of the Healthy Start effort was associated with non-servicedelivery activities, emphasii again that Healthy Start is not only a service delivery program.

Further, the diversity in project designs is reflected in how they spent their funds. Figure II.2 shows that the proportion of expenditures devoted to various categories varied substantially across projects. For example, the percentage of expenditures for services varied from 58 percent to 79 percent. The following chapters analyze in more detail this variation in the types of programs implemented under Healthy Start. We first cover administration and consortium development, then the services delivered under **Healthy** Start, and finally, some of **the** other activities categorized under "other." Throughout this discussion we refer to implementation "success" by which we mean that

FIGURE II. 1

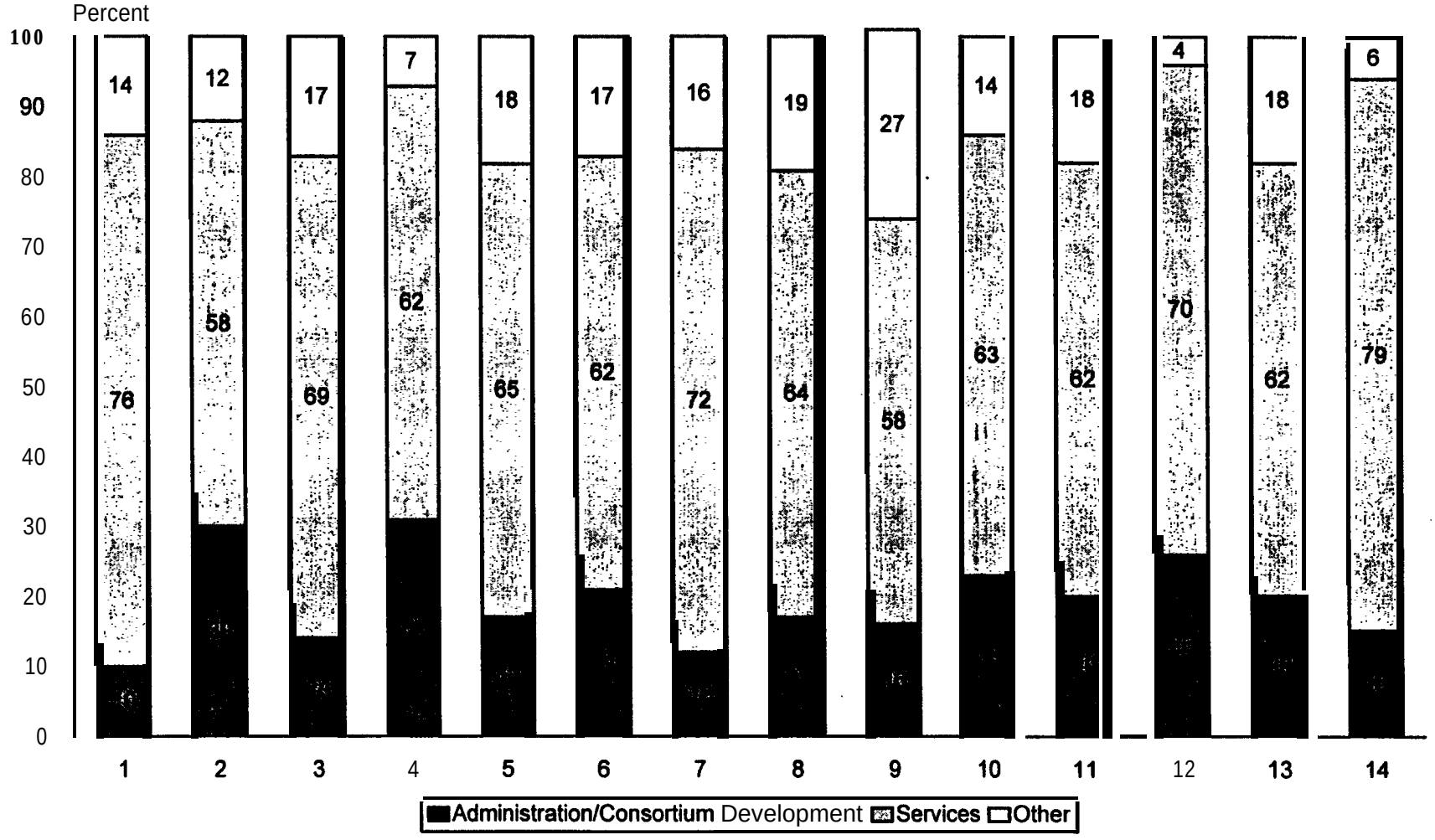
HEALTHY START EXPENDITURES BY EXPENDITURE CATEGORY
FISCAL YEAR 1996



IMR: Infant Mortality Review
MIS: Management Information System
O/CM: Outreach/Case Management

FIGURE II.2

HEALTHY START EXPENDITURES BY EXPENDITURE CATEGORY
BY PROJECT--FISCAL YEAR 1996



1. Baltimore
2. Birmingham
3. Boston
4. Chicago
5. Cleveland
6. Detroit
7. DC
8. New Orleans
9. New York
10. N.W. Indiana
11. Oakland
12. Pee Dee
13. Philadelphia
14. Pittsburgh

projects were able to develop plans and follow those plans for a particular component according to the timeline that they agreed upon with HRSA. The impact of these efforts on infant mortality remains to be assessed.

III. ADMINISTRATION AND COMMUNITY INVOLVEMENT

The Healthy Start grantees have taken a variety of approaches to organizing and managing their projects. This chapter compares these approaches in terms of administrative oversight of the grant, project staffing, and contracting arrangements. All of these measures have affected the successful administration of Healthy Start projects, and each serves as a proxy for the quality of management in each project. As with other aspects of the demonstration, there was variability across projects in these measures. The chapter also describes how Healthy Start grantees have involved their communities in the operation of their projects.

A. ADMINISTRATION

1. Grant Oversight

To implement this new program, Healthy Start grantees developed a variety of administrative arrangements (see Table III.1). The most common location for a grantee (5 of 14 sites) was within a city health department. Baltimore, Cleveland, Detroit, New Orleans, and Philadelphia made this choice. Three grantees were located within county health departments: Birmingham (Jefferson County), Oakland (Alameda County), and Pittsburgh (Allegheny County). Only the grantee for the Chicago Healthy Start project was the state health department. The District of Columbia grantee was an agency that assumed city, county and state functions.

The reliance on health departments for administrative oversight provided several advantages:

- Health departments all had qualified staff to oversee initial project development.
- Health departments' are directly tied to a jurisdiction's political and health care leadership, a relationship that had the potential to encourage the support and involvement of such leaders. This was an advantage to the project as it sought to implement system-wide changes.

TABLE III. 1

ADMINISTRATIVE OVERSIGHT OF HEALTHY START GRANTEES

Project	Grantee	Health Department			Inter-governmental Organization	Other Non-profit
		City	County	state		
Baltimore	Baltimore City Health Dept.	✓				
Birmingham	Jefferson County Health Dept.		✓			
Boston	Boston Trustees of Health and Hospitals					✓
Chicago	Illinois Dept. of Public Health			✓		
Cleveland	Cleveland Dept. of Public Health	✓				
Detroit	Detroit Health Dept.	✓				
DC	DC Dept. of Human Services[b]			✓		
New Orleans	City of New Orleans Dept. of' Health[a]	✓				
New York	Medical and Health Research Assoc. of NYC					✓
N.W. lndiana	NW Indiana Health Dept. Cooperative				✓	
Oakland	Alameda County Health Care Services Agency		✓			
Pee Dee	United Way of SC					✓
Philadelphia	City of Philadelphia Dept. of Public Health	✓				
Pittsburgh	Allegheny County Health Dept.		✓			

'Uses single major nonprofit contractor for administrative oversight.
[b]This agency assumes city, county, and state functions.

- Health departments often helped to sustain certain components of the project when federal funding declined.

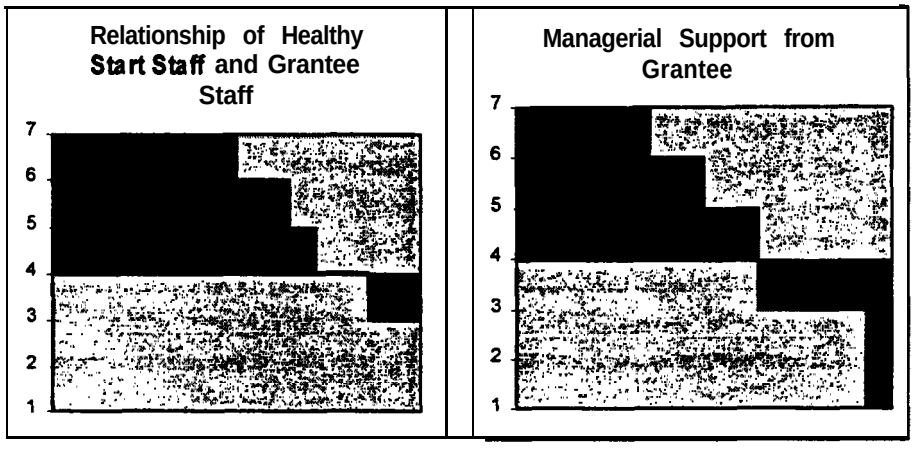
Location within a health department also had some disadvantages:

- Bureaucratic administrative and civil service procedures sometimes slowed hiring and contracting for services, thus impeding the development of a demonstration program with a relatively short timetable.
- Poor relationships in some projects between the local population, providers, and the city, county, or state health department affected implementation.

To address the problems of operating a large demonstration project, where many new initiatives needed to be undertaken quickly, some of the health department grantees relied on private, nonprofit entities as major nonprofit contractors. Such organizations were generally exempt from many of the restrictions associated with operating a project directly within the government. The grantees contracted with such organizations to operate Healthy Start, but line authority for the project remained with the health department. For these three projects (Baltimore, New Orleans, and Pittsburgh), the strategy required the development of new organizations. In the remaining four projects (Boston, New York, Northwest Indiana, and Pee Dee), the grantee itself was an existing nonprofit organization. (The Northwest Indiana grantee-an innovative cooperative formed by four health departments--was relatively new, having received only two small grants prior to receiving Healthy Start funds.)

The managerial support that each Healthy Start project received from the grantee and the relationship between the project staff and grantee staff were identified by site visitors as key to successful program implementation. A strong relationship with and support from the grantee enabled the project to more quickly overcome bureaucratic hurdles, obtain political support, integrate Healthy Start with other local efforts, and leverage federal support with local funding.

The following two charts illustrate that for most projects, site visitors perceived that the relationship with and support from grantees was good. Site visitors felt that almost all project staff had a good or close-to-good relationship with their grantee staff, with 7 of 14 projects scoring 7, and 2 scoring 6. Five projects lacked good managerial support from their grantee.

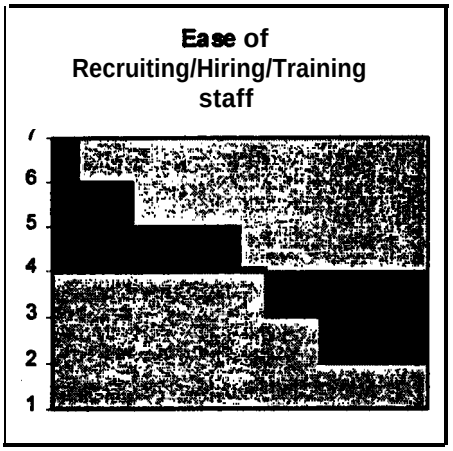


NOTE: **7 is good; 4 is neutral; 1 is weak.**

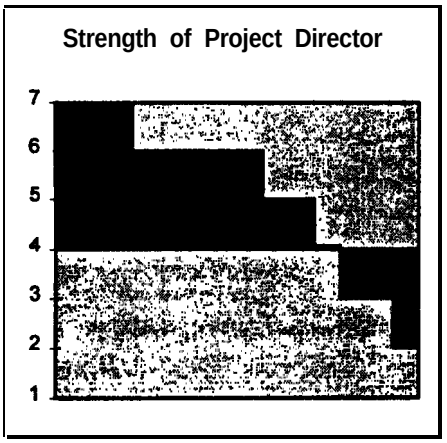
2. Staffing the Healthy Start Project

The first step faced by projects in implementation was recruiting, training, and retaining a high quality staff. To develop a community-oriented initiative, projects often hired individuals who were already familiar with the Healthy Start communities and who reflected the ethnic mix of community residents. The size and qualifications of the staff, which varied substantially by project, were defined in the annual grant renewal applications approved by HRSA. For example, in 1994 at the time of our first round of site visits, the size of the project staff varied from less than 5 to more than 100. **At the time of the site visits, some of the projects were very stretched because their staff was small.** A small administrative staff limited the management of complex functions such as supervising personnel, developing budgets, overseeing the contracting process, staffing the consortium and its committees, and preparing reports and annual continuation applications.

Site visitors observed that almost half the projects had **difficulty** hiring and retaining **staff,** as shown below. Projects pointed to bureaucratic delays in the hiring process, usually imposed on them by their grantee agency, as the major source of these difficulties. The most important staff position was project director, defined as the person with day-today responsibility for administering the project. [1] **This** person was usually the first one recruited, and he or she then led the effort to recruit other staff A strong project director who provided effective leadership to the staff and related well to the diverse Healthy Start organizational constituency (the grantee agency, the consortium, and HRSA) was critical to implementation success. As shown in the chart at the left, most Healthy Start project directors were rated strong by site visitors, and this strength reportedly helped to foster a program with a strong positive image.



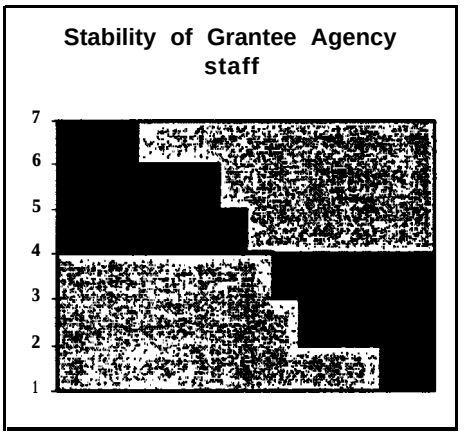
NOTE: **7 is easy; 4 is neutral; 1 is difficult.**

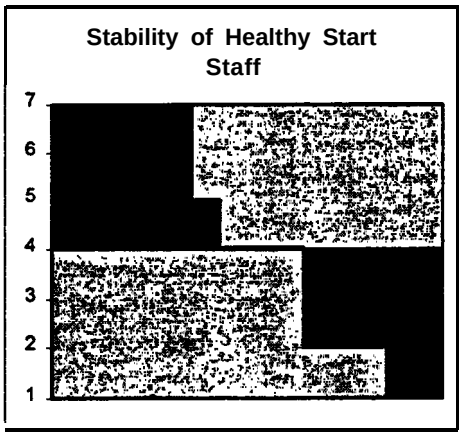


NOTE: **7 is strong; 4 is neutral; 1 is weak.**

The stability of project staff was also a key to implementation success. The following two charts show that turnover in both the grantee and project staff was a problem for about half the projects. When that turnover did occur and was in the most senior positions, it had a negative impact on the timing of implementation or other aspects of administration.

'This title is not used universally or consistently across grantees. Some grantees use the title "executive director," and some have two individuals with titles indicating administrative leadership responsibility. For example, one might be in the grantee agency and the other in the major nonprofit contract agency.





3. **Contracting Arrangements**

Each Healthy Start grantee used one or more contractors (in addition to the major nonprofit administrative contractors) to perform some program functions. Such contracting arrangements helped to:

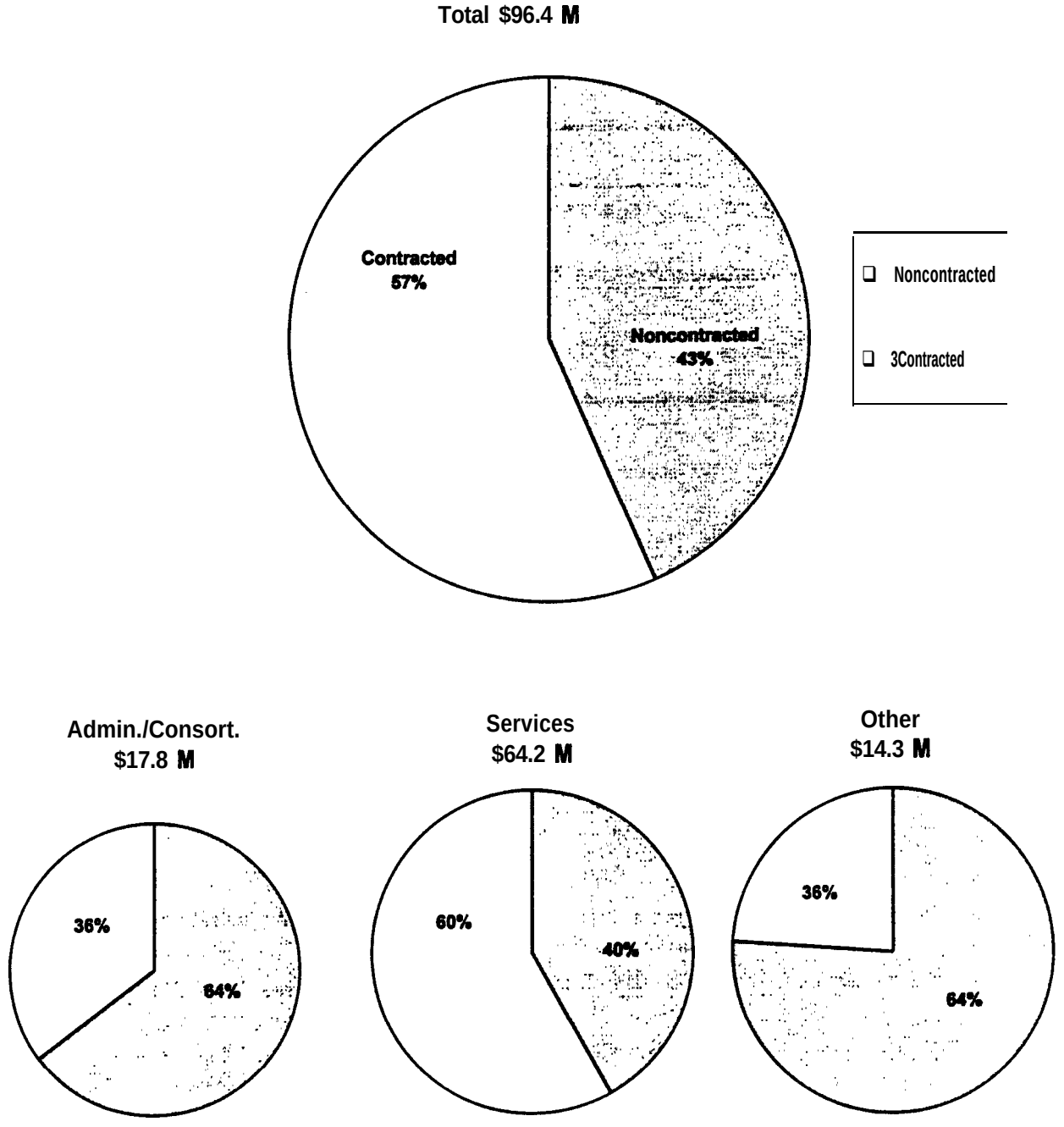
- Provide a mechanism for involving the community and increasing interest in Healthy Start
- Allow the project to be launched without having to hire all personnel immediately
- Capitalize on the existence of providers who already served the Healthy Start population
- Address the goal of using existing community resources to effect incremental change in programs
- Enhance the buy-in of influential service providers and other organizations which had participated in the process of preparing proposals and provided other early support

Guidance from HRSA stipulated neither the functions to be contracted nor the method for selecting contractors. Overall, about 60 percent ($55.5 of $96.4 million) of Healthy Start expenditures in fiscal year 1996 went to contractors (Figure III.1).[2] Administration/consortium expenditures were less likely than services and other types of program functions to be contracted.

*These expenditures do not include the costs for major nonprofit administrative contractors.

FIGURE III.1

PERCENT OF HEALTHY START FUNDS CONTRACTED
BY TYPE OF EXPENDITURE FOR 14 SITES,
FISCAL YEAR 1996 (in millions)



Extensive contracting, particularly for services, challenged central staff, who had to work indirectly through contractors rather than directly with their own staff to ensure accountability for service delivery. As projects matured during the demonstration, they honed their approaches to monitoring contracts, in many instances developing specific protocols for, and hiring staff dedicated to, this function. The distribution of contract expenditures varied by project. For example, Cleveland spent only a small portion of its budget on direct project activities and allocated almost all of its grant award to contracts.

Only Boston and Philadelphia used a competitive process to select all contractors. Nine other projects used competitive bidding for some but not all of their contracts. In some communities and for some services, there were few qualified providers, and a competitive process was not perceived as being necessary or useful. Increasing the service capacity of the existing providers was the preferred strategy in these circumstances.

Competitive bidding had both advantages and disadvantages. Some projects believed that receiving bids from a variety of small community-level providers increased community awareness of, involvement in, and commitment to the project. On the other hand, the competitive process slowed program implementation. It also added to the burden on staff, who were required to develop RFPs and provide technical assistance in the bidding process-especially for small organizations that did not have the capability to prepare proposals.

Although non-competitive contracting facilitated faster program implementation, it made it hard for projects to enforce performance standards, since they lost some of the leverage that comes with recompetition. This form of contracting could also narrow the base of support for Healthy Start by eliminating certain key providers who did not have an opportunity to receive funds.

Irrespective of whether contracting was competitive or not, the structure of Healthy Start created the potential for conflicts of interest. The mandate for a consortium composed of providers and community individuals meant that many potential contract providers also were able to play influential roles at the executive and subcommittee levels of the consortium. Implicit in this dual function was the potential for providers to influence the selection and funding of contracts in their favor. In response, many projects developed explicit conflict-of-interest policies and procedures. However, not all projects strictly or consistently applied those guidelines.

B. COMMUNITY INVOLVEMENT IN HEALTHY START: THE HEALTHY START CONSORTIA AND OTHER STRATEGIES

Community involvement in planning and implementing the projects was a required feature of Healthy Start. From site visits and review of program documents, the national evaluation team observed that, with varying intensity and success, all projects encouraged community involvement through numerous strategies. These strategies fell within two main models: a service consortium model and a community empowerment model.[3] These models are distinguished by both the strategies they used and the type of community members they involved. The service consortium model used membership in the project consortium to involve the community. This strategy was appropriate for and successful in involving community providers and other professionals in the project. The community empowerment model used neighborhood-based consortia, employment, contracts and economic development efforts to involve primarily nonprofessional community members in the project. All projects used a combination of strategies from both models, though the

[3]Community involvement in Healthy Start and the models present here are described in more detail in Howell, Devaney, McCormick, and Raykovich (forthcoming, 1998).

extent to which they did so varied by site. These differences notwithstanding, the models give us a way to conceptualize and evaluate community involvement in Healthy Start.

1. Service Consortium Model

In the service consortium model (Figure **III.2),** projects involved the community in Healthy Start by developing a network of providers who received project funds and who, along with some other community members, worked through the consortium to plan and implement the program in their community. While HRSA required all projects to develop a consortium, the agency did not prescribe the particular features of this body. Instructions to applicants stated, "The consortium must include representation that reflects a partnership of consumers, providers of services, and community organizations and groups, both public and private" (U.S. DHHS 1991). Although HRSA stated that the consortium would be advisory, it was not entirely clear to the projects how a consortium would use its authority relative to a project, that is, whether it would function as a governing board or an advisory group. Nor did HRSA specify the size or composition of the consortium, or the frequency of meetings. Instead, the agency focused primarily on the consortium's role in planning for the initial application and in developing the comprehensive plan for the project.

Healthy Start projects were therefore free to invite a range of individuals to join their consortia. Providers, representatives of government agencies, consumers of Healthy Start services, and other community residents were asked to be members. This broadly inclusive approach to forming consortia **affected** their size, governing style, and structure. Half of the consortia had close to 100 or more members (see Table 111.2). As such, these groups typically functioned more as "town meetings" for disseminating information and less as decision-making bodies, especially early in the project period. Other projects created leaner and more modular consortia, more suited to **decision-**

FIGURE III.2

SERVICE CONSORTIUM MODEL

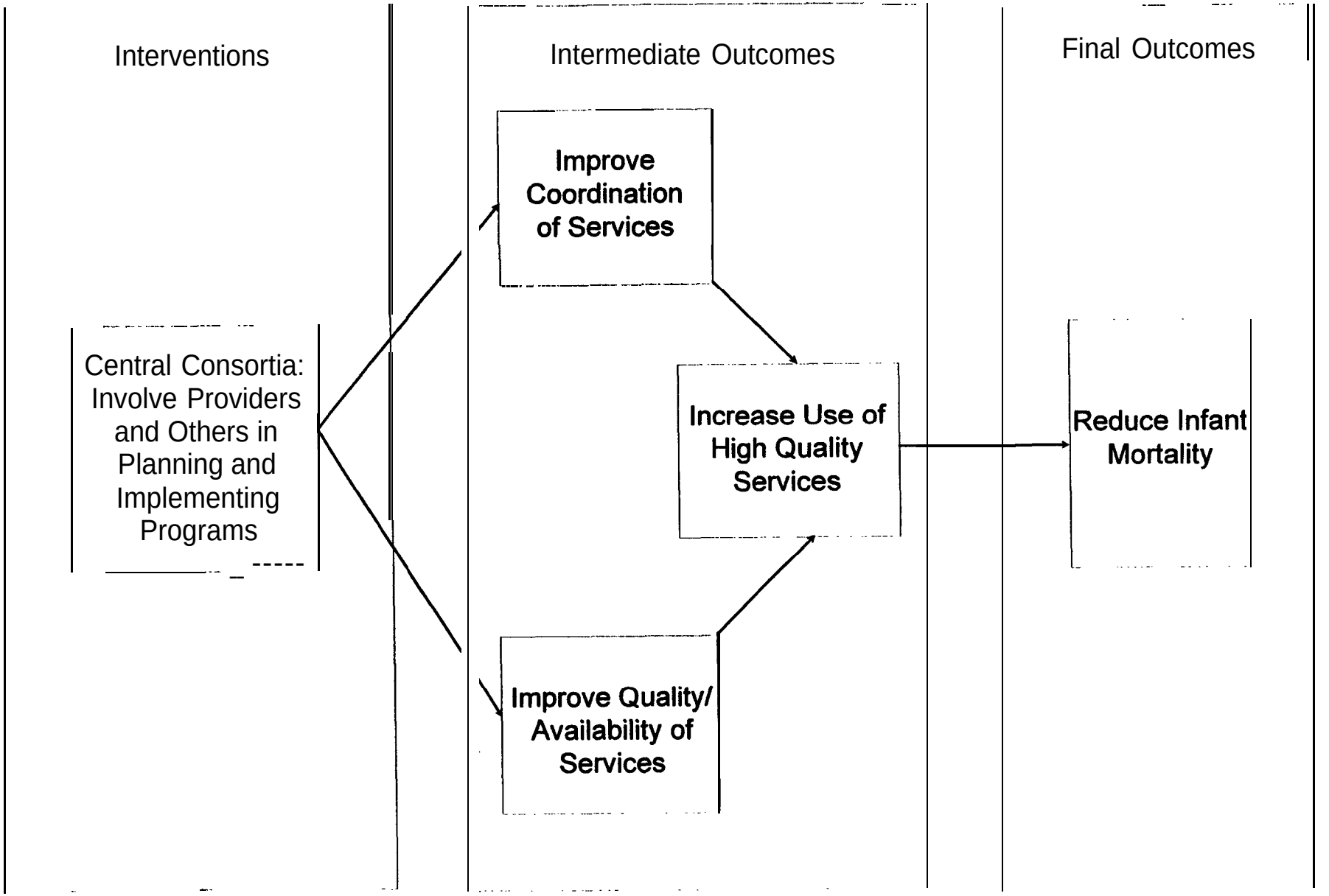


TABLE III.2

CHARACTERISTICS OF HEALTHY START SERVICE CONSORTIA

Sites	Number of Active Committees[a]	Number of Members		Frequency of Meetings		Forum for Decisionmaking	Percent of Attendees at Example Meeting Who Were Providers (Excludes Staff)[b]
		Consortium	Committees	Consortium	Committees		
Baltimore	3	120	I O-20	Quarterly	Bimonthly	No	58
Birmingham[c]	1	None	9	N/A	Bimonthly	No	N/A
Boston	6	300	30	Monthly	Monthly	Yes	50
Chicago	7	96	10	Bimonthly	Monthly	Yes	86
Cleveland[d]	9	None	15-20	N/A	Monthly	Yes	90
Detroit	3	50	8-20	Bimonthly	Bimonthly	No	67
D.C.	6	169	6	Quarterly	Quarterly	No	50
New Orleans	7	86	5-34	Quarterly	Quarterly	No	14
New York	5	100	6	Quarterly	Monthly	Yes	100
N.W. Indiana	3	78	4	Monthly	Monthly	No	96
Oakland	2	12	12-20	Monthly	Monthly	Yes	38
Pee Dee	3	12	5	Monthly	Monthly	Yes	50
Philadelphia	8	150	8	Quarterly	Bimonthly	No	100
Pittsburgh	6	18	20	Monthly	Monthly	Yes	83

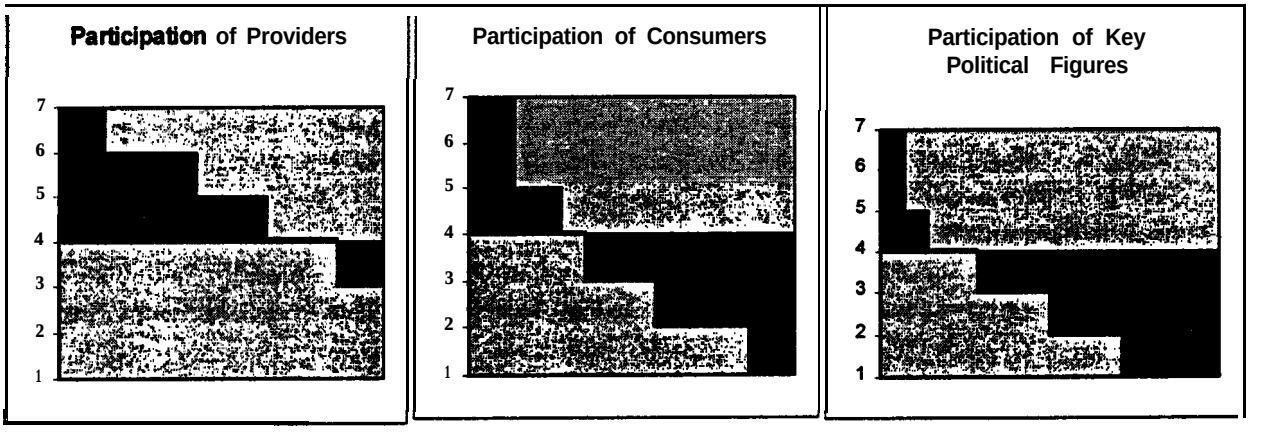
SOURCE: Second round of site visits, January-March 1996, and telephone updates in May-June 1997.

N/A: Not Applicable

[a]Defined as having met at least once in the quarter preceding the site visit or telephone update.
[b]Estimates based on sign-in sheets at the example meeting. Meeting may have been of the full consortium, or a management committee.
[c]Birmingham does not have an active consortium; the consortium was disbanded in June 1996. A small committee provides liaison between the staff and the community.
[d]In Cleveland work occurs in committees and local consortia.

making and to developing plans for sustaining Healthy Start beyond federal funding. Pittsburgh formed an l&member board of directors, and Pee Dee built a 14-member regional council. Cleveland had an executive council, an administrative management group, committees, and several local (neighborhood-level) consortia but no large central consortium. In Birmingham, severe conflict between a small number of consortium members and staff led to the dissolution of the large central consortium in June 1996. A small committee now acts as the liaison between staff and the community.

As shown in the charts that follow, involving providers in the consortia was much easier than involving other community members or key political figures, partly because those who provided services funded through Healthy Start had a greater stake in the project and saw consortium involvement as a way to protect their interests. In fact, typically more than half, and in some sites all, of the people at the meetings we attended were providers.



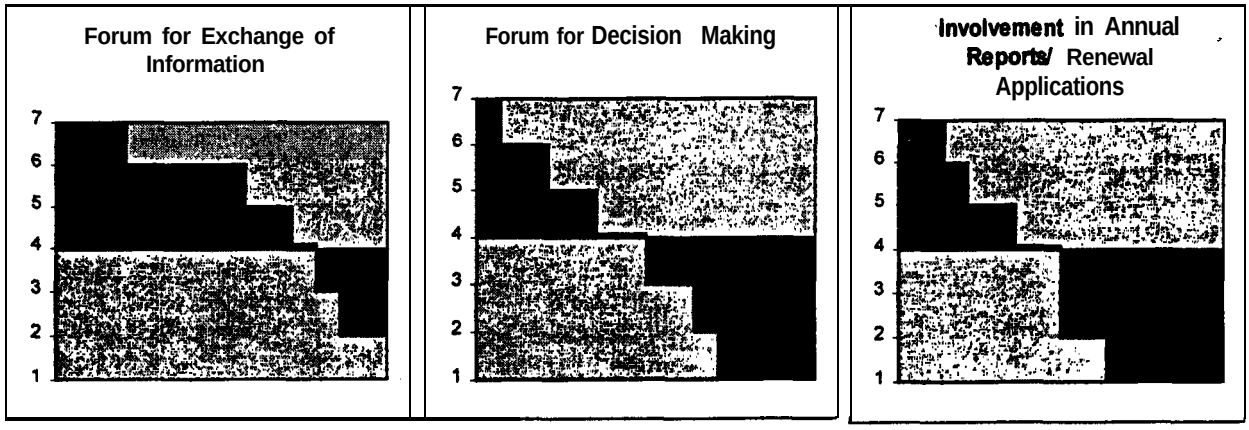
NOTE: 7 is strong; 4 is neutral; 1 is weak.

This general lack of success in involving community members in the consortium occurred despite concerted efforts by many projects, such as reimbursing people for meeting-related travel and child care expenses. Persuading individuals to volunteer meant convincing them of the personal

benefits of their efforts, and we found that infant mortality was not as personally compelling.to community residents as other community issues such as poor housing, unemployment, and violence.

When community interest in and enthusiasm for the initial broad-based Healthy Start consortium waned, much of the work of these bodies moved to committees in most projects. The committees were more effective decision-making entities because they were smaller (about 10 to 20 members) and met more regularly. Although committees proved to be a more efficient alternative to a large consortium, they did not foster broad-based community involvement. Instead, their membership was dominated by staff and providers or representatives of other organizations that received Healthy Start funds.

The site visits allowed us to observe whether community involvement in planning was an ongoing process or primarily an activity of the first planning year. The range of approaches to community involvement in planning was wide. In some projects, there was almost no involvement of the consortium or community groups (residents, consumers) in ongoing planning, although contract providers had considerable discretion in planning how to use their funds. But in projects like Boston, Chicago, and New York, planning was a joint effort between staff and committees of the consortium. In general, however, committee involvement in planning primarily ensured that providers and agency representatives, rather than consumers, were involved. The following charts illustrate, with some exceptions, that site visitors found the consortium to be useful for exchanging information; however, it was generally neither a decision-making body nor a strong influence on project decisions.



NOTE: 7 is strong; 4 is neutral; 1 is weak.

2. Community Empowerment Model

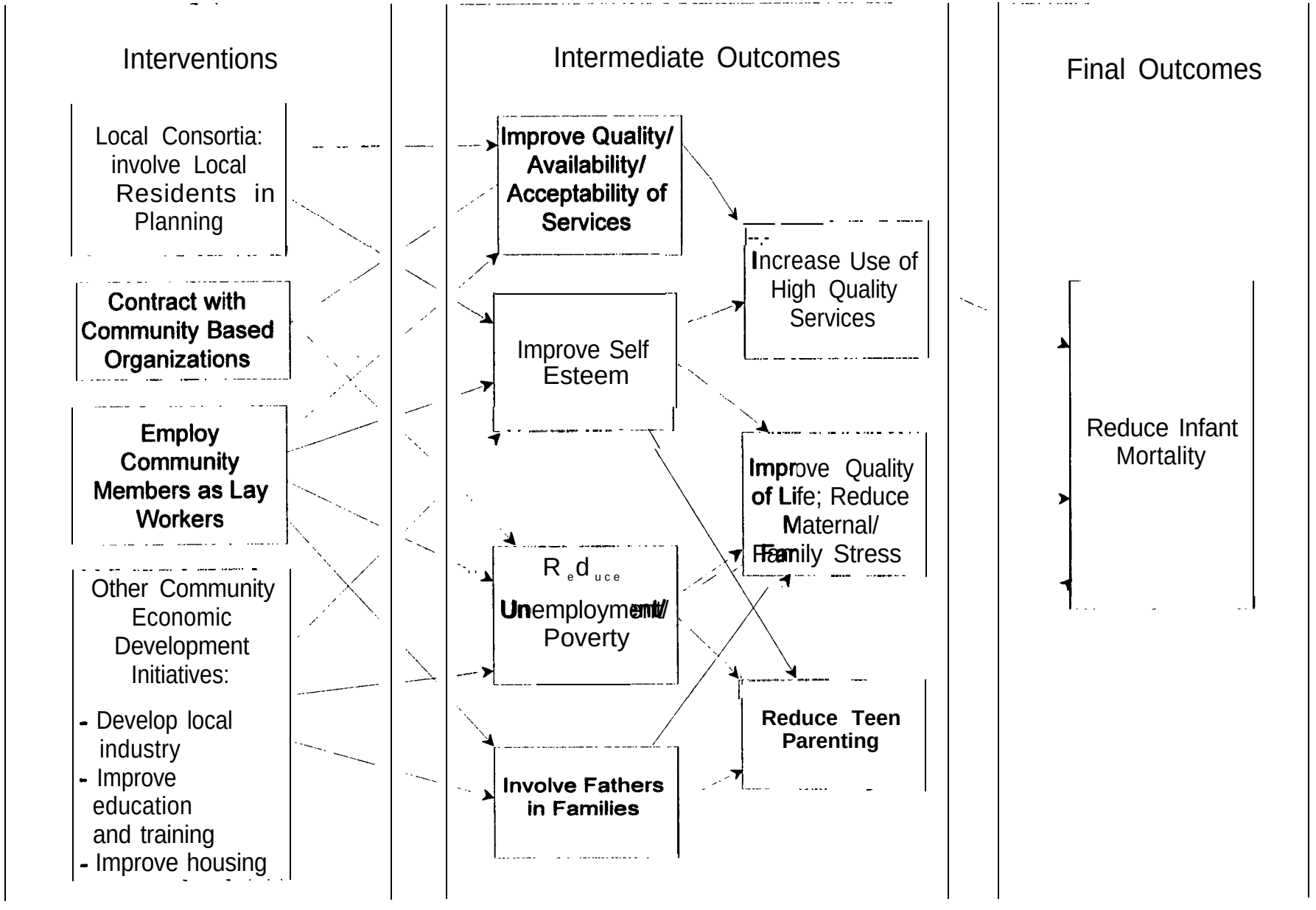
The community empowerment model of community involvement (Figure 111.3) had four additional strategies for involving community members: (1) engaging people in planning efforts through neighborhood-based groups, (2) contracting with community-based organizations for services," (3) employing community residents as lay workers in the Healthy Start program, and (4) creating other community economic development initiatives.

Compared with the service consortium model, the impact of the strategies in the community empowerment model is more complex and difficult to measure in an evaluation because of the more indirect linkage between interventions and infant mortality, and because of the sheer number of intermediate outcomes. In addition, all linkages involve the demonstrated-but poorly understood--relationship between poverty and infant mortality. Indeed, advocates for this model would argue that, absent interventions that target poverty, Healthy Start would merely be "more of the same" in terms of using service-based interventions that have been tested but not shown to reduce infant mortality.

"These include small nonprofit, or at times for-profit, organizations that are owned and operated by community members; this category also includes larger organizations such as the Urban League that are neighborhood based and advocate for community Concerns.

FIGURE III.3

COMMUNITY EMPOWERMENT MODEL



All of the projects adopted strategies from the community empowerment model to involve the community in Healthy Start. The first strategy was to build local consortia with a greater representation of the community and consumers. Eleven projects created local consortia, ranging from one in Birmingham and Chicago to 11 in Cleveland (Table 111.3). These groups were typically neighborhood based, although those in Pee Dee and New York served a larger geographic area. In Pee Dee, each of the six counties had its own consortium. While projects still attempted to involve community members in their central consortia, none succeeded in sustaining the involvement of nonprofessionals beyond small levels of representation.

Local consortia, on the other hand, met in the community, though not necessarily regularly, and members tended to be residents, making the meetings both more accessible and less intimidating. Some of these groups were established for other purposes and predated Healthy Start, as in New York, and consequently often addressed a range of community issues in their meetings. They became forums for information-sharing and community health education. Some also had special responsibilities, such as selecting community applicants for project jobs. Others handled small budgets to fund Healthy Start-related community events, such as health fairs and other outreach activities. Still others were used to increase the self-confidence and speaking skills of community residents, In New York, the Central Harlem site organized a "speakers bureau" with regular classes to train community residents in public speaking.

The effort to develop grass-roots community involvement was an intensive one. Project staff needed to identify local residents as potential members, recruit them, develop meeting agendas and locations, attend meetings, and prepare minutes and reports. Local consortia that became very active, as in Pee Dee, required a large amount of staff effort. In addition to the energy needed to organize the group, the ability to galvanize neighborhood support around issues was a necessary and special

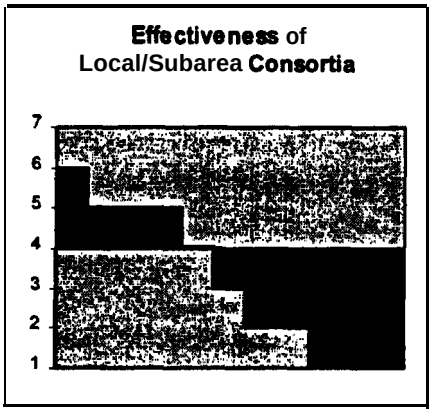
TABLE III.3

HEALTHY START COMMUNITY EMPOWERMENT

Project	Number of Active Local Consortia	Number of Contracts with CBOs	Number of Lay Outreach/Case Management Workers Employed
Baltimore	2	16	95
Birmingham	1	13	22
Boston	0	51	Not Available
Chicago	1	17	60
Cleveland	11	4	97
Detroit	3	12	16
District of Columbia	0	13	36
New Orleans	9	10	101
New York	3	27	25
N.W. Indiana	4	5	18
Oakland	3	21	7
Pee Dee	6	37	4
Philadelphia	0	65	16
Pittsburgh	6	11	22

SOURCE: Second round of site visits, January-March 1996, and telephone updates, May-June 1997.

CBO = Community-based organization.



NOTE: 7 is successful; 4 is neutral; 1 is unsuccessful.

skill. Even projects that did have staff trained in community organization were short on such resources. Consequently, as shown at the left, local consortia were viewed as successful by site visitors only in a few projects, although the successful local consortia demonstrated a very promising strategy for community involvement.

A second strategy in the community empowerment model was to contract with community-based organizations (CBOs). A CBO is any nonprofit agency or business in the service area that is closely tied to the community because it is owned by a resident, employs community residents, or is traditionally active in the community. This strategy was very popular in some projects. Boston, for example, had 5 1 contracts with CBOs, and Philadelphia had 65 (see Table III.3). Projects contracted with a variety of types of CBOs. For example, Cleveland contracted with some large organizations such as the Neighborhood Centers Association. In other projects, churches provided outreach, health education, or social services--usually for relatively small dollar amounts.

Contracting with CBOs, especially smaller ones, was a challenge. Because CBOs have limited administrative resources, their staff had little time to write grant proposals or to prepare progress and financial reports. Local project staff often had to provide technical assistance in grant writing. Some projects also had to modify the standards they might have otherwise used for oversight or contract monitoring for very small grantees, opening them up to the risk that came with the absence of accountability for funds or program operations. While there have been no widespread problems, two projects had to cancel contracts with CBOs due to financial or performance problems.

In addition to using local consortia and CBOs, all projects employed community residents. to some degree (Table 111.3). Baltimore, Cleveland, and New Orleans each employed about 100 local women and men as neighborhood outreach workers in 1996, making Healthy Start a highly visible source of jobs for community residents and increasing the value of the project in their eyes. Projects that hired large numbers of residents also attempted to define a career path for them. For example, some community outreach workers in Cleveland were trained to deal with substance abuse in some capacity, while others were promoted to outreach worker supervisors. Several projects successfully hired and trained former welfare recipients, and others worked closely with local employment and job training programs such as those funded through the Job Training Partnership Act.[5]

Most projects developed their own, often extensive, training programs for lay community workers--largely in response to the fact that the available positions involved extensive record-keeping responsibilities and therefore had relatively high literacy requirements. Projects found that extensive training, such as classroom training for a number of weeks followed by on-the-job training for several additional weeks, made their workers more effective. Projects also encouraged their community employees to complete high school or the GED, or to continue in college, with some providing workers with an opportunity to earn credits for courses. Most projects also provided continuing training and mentoring, and they kept the ratio of lay to professional workers relatively low (e.g., 4 to 1).

In addition to employing community residents in Healthy Start, some projects launched a number of other community economic development initiatives. For example, in the Pee Dee region where economic development was a major community concern, a full-time economic development director, hired by Healthy Start through contract with the State Department of Commerce, worked

[5]Simon and Raykovich (1995) describe the use of community outreach workers in more detail.

on bringing jobs to the communities. And in New York, Healthy Start CBO subcontractors worked to improve housing and provide job training.

The relatively short demonstration period, the historically skeptical attitude of low-income neighborhood residents toward government agencies, the pressing nature of issues other than infant mortality in the lives of local residents, and the labor-intensive effort of staffing a consortium have made it difficult for projects to involve communities. Despite these difficulties and the resulting frustration experienced by many of the projects, most have shown a true commitment to the process and feel that any improvement in prenatal care and birth outcomes will be due, in part, to the degree to which the community involvement strategies succeed. Community involvement itself is a developmental process and may slow program development. Therefore, evaluations that are designed to measure short-term outcomes may not capture the impact of community involvement strategies.

IV. SERVICES PROVIDED TO HEALTHY START CLIENTS

Two-thirds of the Healthy Start effort, as measured by program expenditures, was devoted to delivering services. Most of these services were provided to a defined population (or "clients"), but a few services such as outreach and health education were provided to larger community groups that cannot be easily defined and counted. This chapter provides descriptive information on the service delivery programs funded through Healthy Start. It presents more detail on clients and services for a subset of those served, that is, pregnant women, mothers of infants under one year of age, and infants who received selected Healthy Start services. The primary source of information on clients and services is the client-level data set known as the Minimum Data Set (MDS). Although the MDS does not have detailed information for all people served by the program, the individuals included in the MDS are those for whom services designed to reduce infant mortality are most likely to have an impact. Also, for almost all projects, the MDS includes most of those who were directly served by Healthy Start.

A. HEALTHY START CLIENTS

Table IV. 1 shows the number of prenatal and postpartum maternal and infant clients who were ever served by Healthy Start during fiscal year 1996.' These data are derived from the MDS produced from each project's management information system. Difficulties encountered by the projects in implementing these systems have impeded the development of accurate program statistics for earlier years. However, we believe that fiscal year 1996 statistics are reasonably accurate. Each

'These totals exclude those served by Healthy Start who were not pregnant or who did not have an infant during that year, that is men, others (such as adolescents) who were not pregnant or parenting, and young children above the age of one.

TABLE IV. 1

NUMBER OF HEALTHY START MATERNAL AND INFANT CLIENTS BY PROJECT--FISCAL YEAR 1996

'Project	Maternal Clients	Infant Clients	Total Clients	Number of Births in 1995	Ratio of Maternal Clients to Births'
Baltimore	1,351	679	2,030	809	1.67
Birmingham	2,160	1,822	3,982	2,912	.74
Boston	2,557	1,280	3,837	4,455	.57
Chicago[b]	758	1,782	2,540	5,316	.14
Cleveland	3,691	3,596	7,287	4,712	.78
Detroit	1,306	386	1,692	6,618	.20
D.C.	2,316	2,316	4,632	2,870	.81
New Orleans	1,717	1,038	2,755	3,166	.54
New York	1,412	817	2,229	9,287	.15
N.W. Indiana	2,558	1,987	4,545	4,403	.58
Oakland	1,003	638	1,641	3,713	.27
Pee Dee	440	345	785	3,514	.13
Philadelphia	3,828	3,301	7,129	4,368	.88
Pittsburgh	653	1,256	1,909	3,158	.21
TOTAL	25,750	21,243	46,993	59,301	.43
Average Number of Clients Per Project	1,839	1,517	3,357	--	--

SOURCE: MDS client-level data from Healthy Start projects for counts of clients. Birth certificate files from states for counts of births.

[a]Note that the ratio of maternal clients to births should not be interpreted as a "penetration rate" since maternal clients include both those who gave birth during the year and those who were pregnant during the year. The ratio does, however, provide a rough approximation of the relative scope of the fourteen projects.

[b]Chicago project staff noted that their maternal clients are not all included in the MDS due to continuing data system problems.

data submission was reviewed for completeness, and only those variables for. which a high percentage of clients had valid responses were analyzed. Consequently, the variables included here represent a greatly limited subset of the entire MDS.

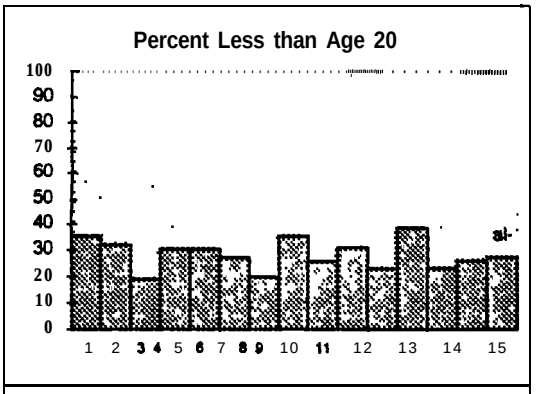
Fiscal year 1996 was a year in which projects were fully operational in delivering services, so Table IV.1 provides a reasonable representation of the volume of mothers and infants served annually by the program. As shown, each project served an average of about 3,300 mothers and infants during this program year, or about 45,000 women and infants across all 14 projects. The size of the projects varied considerably in terms of number of pregnant women and infants served--from over 7,000 in Cleveland and Philadelphia to under 1,000 in Pee Dee, which operated several adolescent prevention programs whose clients were not included in the MDS statistics.

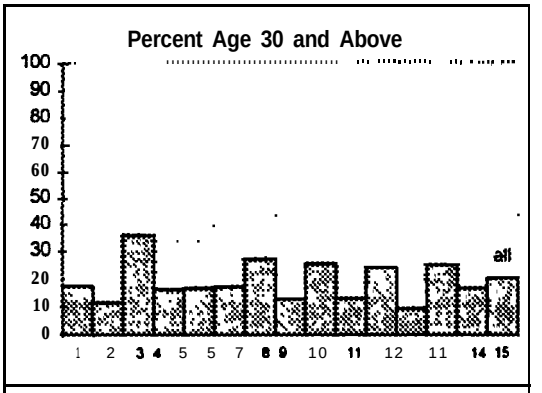
The table also shows the ratio of maternal clients to births in 1995. This is not a "penetration rate," since both women who gave birth and those who were pregnant are included in the count of maternal clients, and the time periods for client counts and births differ somewhat. However, the ratio illustrates that the projects did differ greatly in the degree to which they served almost all, most, or few of the pregnant/postpartum women in their project area. It is important to remember that some projects did not intend to reach all women but targeted certain subgroups.

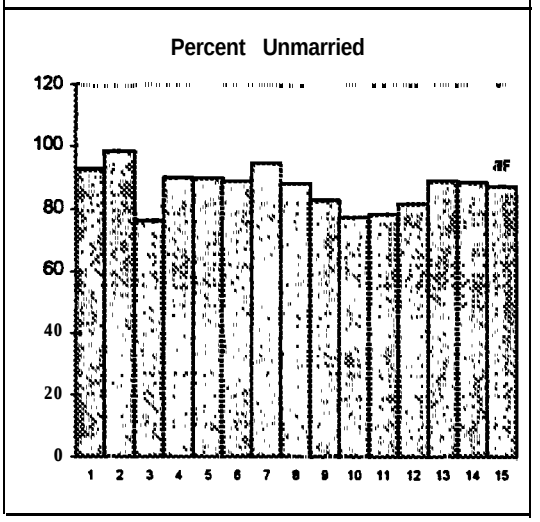
The Healthy Start clients were a very high-risk group demographically, as shown in Figure IV. 1. More than a quarter were under age 20, about 85 percent were unmarried, and about half had not finished high school. Additionally, almost all were members of a minority group. In contrast,

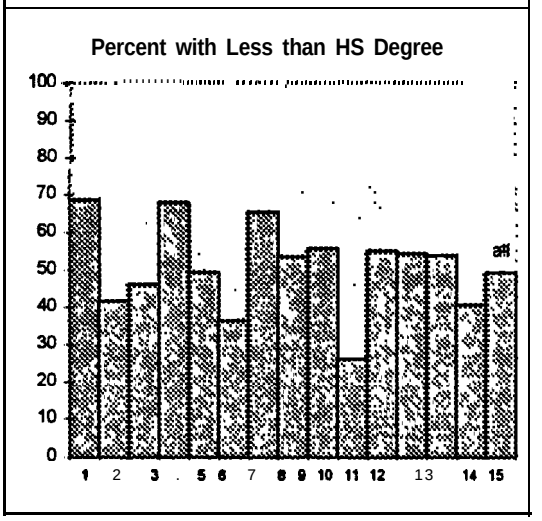
FIGUTEIV.l

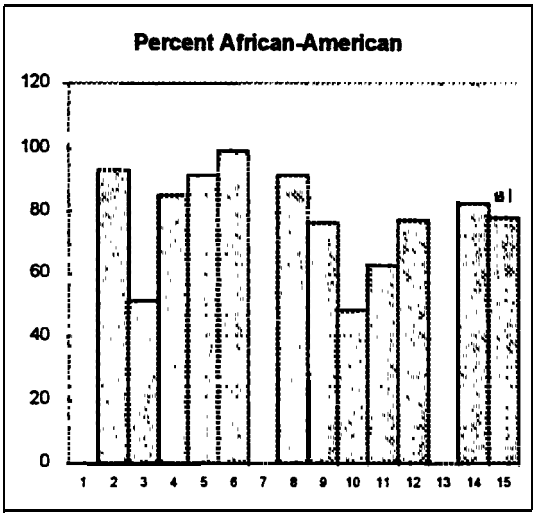
DEMOGRAPHIC CHARACTERISTICS OF HEALTHY START MATERNAL CLIENTS

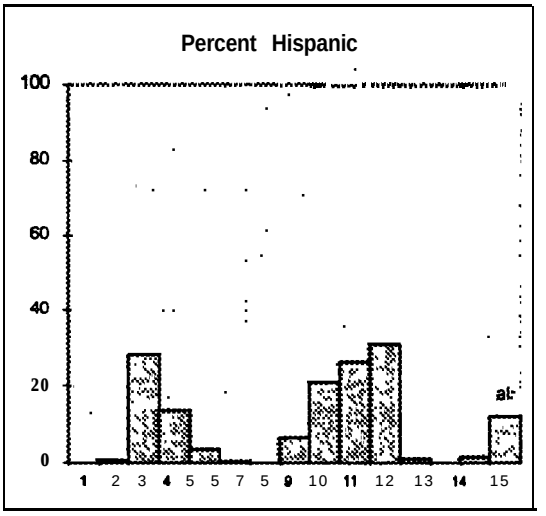












1 Baltimore; 2 Birmingham; 3 Boston: 4 Chicago; 5 Cleveland; 6 DC; 7 Detroit.; 8 New Orleans
9 New York; 10 NW Indiana; 11 Oakland; 12 Pee Dee; 13 Philadelphia; 14 Pittsburgh

NOTE: Data on race/ethnicity are unavailable for Baltimore, Detroit, and Philadelphia.

the proportions of all women in each of these demographic categories who delivered nationally during a similar time period were much lower?

Healthy Start client characteristics also varied considerably across projects. For example, in Pee Dee, about 40 percent of maternal clients were adolescents, compared with only about 20 percent in Boston and Detroit. The latter two sites, plus New York and Oakland, served a higher proportion of older mothers.

To add depth and texture to these statistics, we conducted focus groups with Healthy Start clients and providers in early 1996 (approximately the mid-point of fiscal year 1996).[3] Providers described their typical Healthy Start clients and the problems they faced. Clients offered another perspective on their lives and struggles. We learned that the typical Healthy Start client was from an impoverished area, received some form of public assistance, was unemployed, lacked a formal education or job training, and was young and raising or expecting to raise her children alone. Some had criminal records (prostitution, shoplifting), others were homeless (especially in the heavily urban project sites), and still others had some form of mental illness or substance abuse problem. A small number were more educated and employed but also faced substance abuse problems. While racial and ethnic minorities were dominant in most projects, substantial numbers of white clients were served by some projects.

One group of providers talked about the differences between adolescent and older clients. The younger women, they reported, more often had unplanned pregnancies but generally had access to

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[2]In 1994, 13 percent of U.S. bii were to adolescents, 33 percent were to unmarried mothers, 16 percent were to black mothers, 17 percent were to Hispanic mothers, and 23 percent were to those who did finish high school (Ventura et al. 1996).

[3]Appendix C provides a description of the focus groups, including the number of attendees and their characteristics.

more support services in the community, whereas the older clients (women in their 30s and 40s), many with several or more children, were more difficult to get into services, in part because they believed they did not need them.

Clients in rural areas faced different obstacles from their counterparts in more urban locations (the Pee Dee project is predominantly rural). Isolation, resistance to change, inadequate supply of medical providers, and limited transportation were some of the more difficult problems in rural areas.

Violence was another problem that was worse in some project areas than others. Although all of the projects contended with crime, including domestic violence, some projects confronted major problems related to gang violence, as reflected in the following comment.

> ***[We may have to assist] if they live in a building that is run by a particular gang, and in order for them to get where the services are provided they would have to cross a certain area that is run by another gang. So its a safety issue just for them to get to us....Or the significant other, the father of the baby, is usually in the gang. Or her brother's in the gang, or she's identified with the gang member, and that's where the safety issue comes in***

Providers said that their clients often feel hopeless and have low self-esteem, in part because of difficulties related to poverty and their surroundings:

> ***The typical Healthy Start client that I've seen feels hopeless or helpless.***
>
> ***You're dealing with a lot of women with a low self-esteem, just from how they went through society in the ghettos. You have to work on that and encourage them. That's what blocks a lot of them from going back to school; it's fear.***

Housing problems (lack of or otherwise inadequate housing) were cited as a major issue, particularly in higher-rent urban areas and areas in which gentrification was displacing "original" residents:

I've got a list of my girls all with scratched out numbers-they have got 15 different phone numbers because they go from place to place and end up here. Get your services, come back out, maybe&ally get housing. The housing lists are two years long.

Fear and desperation were common themes that emerged as clients talked about how they reacted to their pregnancy and the issues that moved them to become involved in Healthy Start:

You don't have any job. You got the bills, You're like, 'Oh my God the rent.' The lights, the gas, the heat-this is stuff that has to be paid When you get through with this, then you have the babies. You have to take care of your baby. If there isn't anyone helping you, what are you going to do?

I was real scared after not having had a child for 14 years and finding out I was pregnant. My job was just terminated and I didn't know what else was going to happen. At the time I had no medical insurance. That's when I got introduced to the program and they offered me a whole lot of help that I'm real grateful for.

Point blank what is there around the neighborhood that supports a mother? Nothing....It's terrible how you go to the store now and you can get drugs right at the corner store. That's not safe at all...they are going around asking ten year olds if they want to buy some weed. That's not right.

I was so young I didn't know what I was going to do.

I'm a recovering addict....I am three years clean. To have another baby was just outrageous to me....I was very depressed. I didn't know how I was going to deal with it. But I'd just like to say that I made the decision to have the baby, and Healthy Start helped me live with it.

When I had my baby, the baby's father was giving next to nothing and Healthy Start helped me get on my feet. They aided me in getting public assistance. They have been really good to me.

Many clients talked about their concern for their health and the health of their baby. They worried about health problems such as gestational diabetes, gallstones, pancreatitis, anemia, high blood pressure, and being underweight. They faced other problems as well, such as abusive relationships, substance abuse, fear of hospitals, poor eating habits, being unemployed or still in high school, lacking money or health insurance, having had an abortion already, and having lost a child

either to death or to the foster care system. And they worried about their parenting knowledge, their ability to love and nurture their children, and their finances.

B. HEALTHY START SERVICES

1. Outreach and Case Management[4]

All projects identified the need to increase the use of and coordinate appropriate services during pregnancy and infancy. Although efforts to do this were variously known as "outreach" or "case management," the definition of these functions and the intensity with which they were implemented varied from project to project and, within projects, across providers. For example, outreach could mean the intensive door-to-door canvassing used by a number of projects, or it could mean appointment-reminder post cards and telephone calls that some medical providers offered. On the other hand, the terms often refer to similar functions. So while we refer to them together as O/CM, it is important to remember that they are defined differently from site to site.

All Healthy Start projects offered some type of O/CM services. Eight of the 14 projects had essentially universal O/CM, meaning that almost all Healthy Start clients received some O/CM services. These projects considered O/CM as the core services of the project, receiving primary attention in project planning. Intake into O/CM constituted intake into the Healthy Start program. In the remaining seven projects that did not have universal O/CM, such services were just one category of service that Healthy Start funded, and the circumstances under which a woman received such services varied. In these projects, a Healthy Start client (someone who received Healthy Start-funded services other than O/CM) would not always go through a formal intake process.

[4]We provide a brief overview of this important service here. More detail will be included in a forthcoming report, "Case Management for Low-Income Pregnant Women and Children: Lessons Learned from Healthy Start."

In contrast to staff in the more traditional social work and nurse home-visiting programs with similar goals, many staff in Healthy Start O/CM programs were "lay" workers. This term refers to individuals who did not have specific professional-level training (college-level or above) but who received training either on the job or, in most projects, through a special Healthy Start training program. These workers were also very often residents of the Healthy Start community (Simon and Raykovich 1995).

Some Healthy Start projects developed and implemented protocols for outreach and case management to coordinate activities across the various providers early in their program. Other projects developed these protocols over the course of project implementation. By the fifth project year; nearly all had developed protocols of some sort, as they learned how important it was to provide oversight of service delivery in order to monitor contracts and assess the quality of services. In some cases, these protocols built on previous approaches. For example, in the areas served by the Pee Dee project, case management services were traditionally provided by local health departments and community health centers under Medicaid-funded programs that predated Healthy Start. In adopting the protocols used by those programs, the project ensured that Medicaid reimbursement would be available for such services.

In some projects, such as Chicago, different O/CM providers delivered services in different ways prior to the project. Healthy Start O/CM services in Chicago were provided by five case management agencies throughout the service area, each using a different approach to case management. The project initially developed guidelines for the provision of case management services across all five sites but had difficulty ensuring that all providers followed these guidelines. By the fifth year, the project reported increased success in implementing standard protocols regarding risk assessment, the assignment of women to various case management programs

depending on their level of risk, and frequency and types of contacts once women were enrolled-in the project.

On the other hand, Philadelphia contracted with 65 community agencies to provide a range of services, including O/CM, and did not initially require all contractors to use a standard protocol for the provision of services. During year 5, however, the project developed "A Blueprint for Program Development and Implementation for Outreach and Homevisiting Programs" in collaboration with O/CM providers. This document provided guidelines for outreach and home visiting programs while giving them flexibility to meet their community-specific needs. Furthermore, all providers were monitored to ensure that they met performance standards within the scope of their contract.

Table IV.2 shows the number of maternal Healthy Start clients, the number and percent receiving O/CM in FY 1996, the total expenditures for O/CM services (either directly by projects or through contracts) based on the fiscal year 1996 expenditure reports discussed earlier, the average expenditure per client receiving O/CM services, and the average number of O/CM contacts per month. While patterns varied, projects that had higher numbers of contacts generally had a higher average expenditure per O/CM client. Across all Healthy Start projects for which we have data, there was an average of 1.5 face-to-face contacts per month and 1.4 telephone contacts per month for maternal clients who entered Healthy Start during fiscal year 1996. The average expenditure for O/CM per maternal client was $1,909 for fiscal year 1996.

It is important to emphasize that the data on number of contacts and expenditure per client should be viewed with caution. First, on the basis of our review of O/CM records, the average number of monthly contacts appears to be underreported, especially in some projects such as Cleveland. One reason for this is that the MDS does not allow for disenrollment before an infant is a year old. However, some women included as "clients" in the calculation of rates were not

TABLE IV.2

OUTREACH/CASE MANAGEMENT IN HEALTHY START
FISCAL YEAR 1996

	Number of Maternal Healthy Start Clients	Clients Receiving O/CM in FY 1996				Average Number of Contacts per Month for Those With Ahy Contacts*		Average Caseload Per Healthy Start O/CM Worker	
		N	Percent of Total	Expenditures for O/CM ($1,000)	$ per Client	Face-to-Face	Phone	Prof.	Lay
Baltimore	1,351	1,349	99.9	5,298	3,927	1.9	1.3	125	25
Birmingham	2,160	576	26.7	534	927	N/A	N/A	--	40
Boston	2,557	1,366	53.4	2,207	1,616	1.4	1.0	<-------varies------->	
Chicago[b]	758	758	100.0	3,230	4,261	1.8	1.0	45	45
Cleveland	3,691	3,619	98.0	3,061	846	0.9	0.3	240	30
DC	2,316	1,182	51.0	1,808	1,530	2.3	2.1	100	36
New Orleans	1,717	1,620	94.4	3,584	2,212	0.6	1.2	230	13
New York	1,412	1,412	100.0	2,591	1,835	1.5	1.3	25	25
NW Indiana	2,558	2,337	91.4	1,654	708	2.2	1.6	60	60
Oakland	1,003	1,003	100.0	483	482	0.5	0.8	25	--
Philadelphia	3,828	514	13.4	1,981	3,854	0.4	N/A	100	25
Pittsburgh	653	653	100.0	2,410	3.691	0.9	2.3	so	75
Total	24,004	16389	78.7	28,841	1,760	1.5	1.4	92	35

SOURCES: (1) Healthy Start Minimum Data Set (clients and contacts); (2) Project expenditure report ($ for O/CM); (3) site visits (case loads)

NOTE: Data on case management was unavailable for Detroit and Pee Dee.

"Calculated on the subset of clients who entered the project in FY96 to preclude contact prior to FY96 from the total. The average is defined as the total number of contacts with the client divided by the number of months in FY96 that the client was enrolled in Healthy Start.

[b]Chicago project staff noted that their maternal clients are not all included in the MDS due to continuing data system problems.

N/A: Not Available.

actively receiving services. As with other MDS challenges, this problem has improved with time. In Oakland, for example, clients who have no contact with Healthy Start for 60 days are now automatically disenrolled.

Also, the number of people receiving Healthy Start and O/CM services is probably understated to an unknown degree causing an artificially high average cost per client. This problem was noted by Baltimore, Cleveland, and New York.

According to the judgement of site visitors, 6 of the 14 projects succeeded in implementing both strong outreach and case management components. Another 5 had either a strong outreach or a strong case management component, but not both. Projects that had implemented both components were characterized by a close linkage between identifying and recruiting women and providing them with coordinated services.

2. Support Services

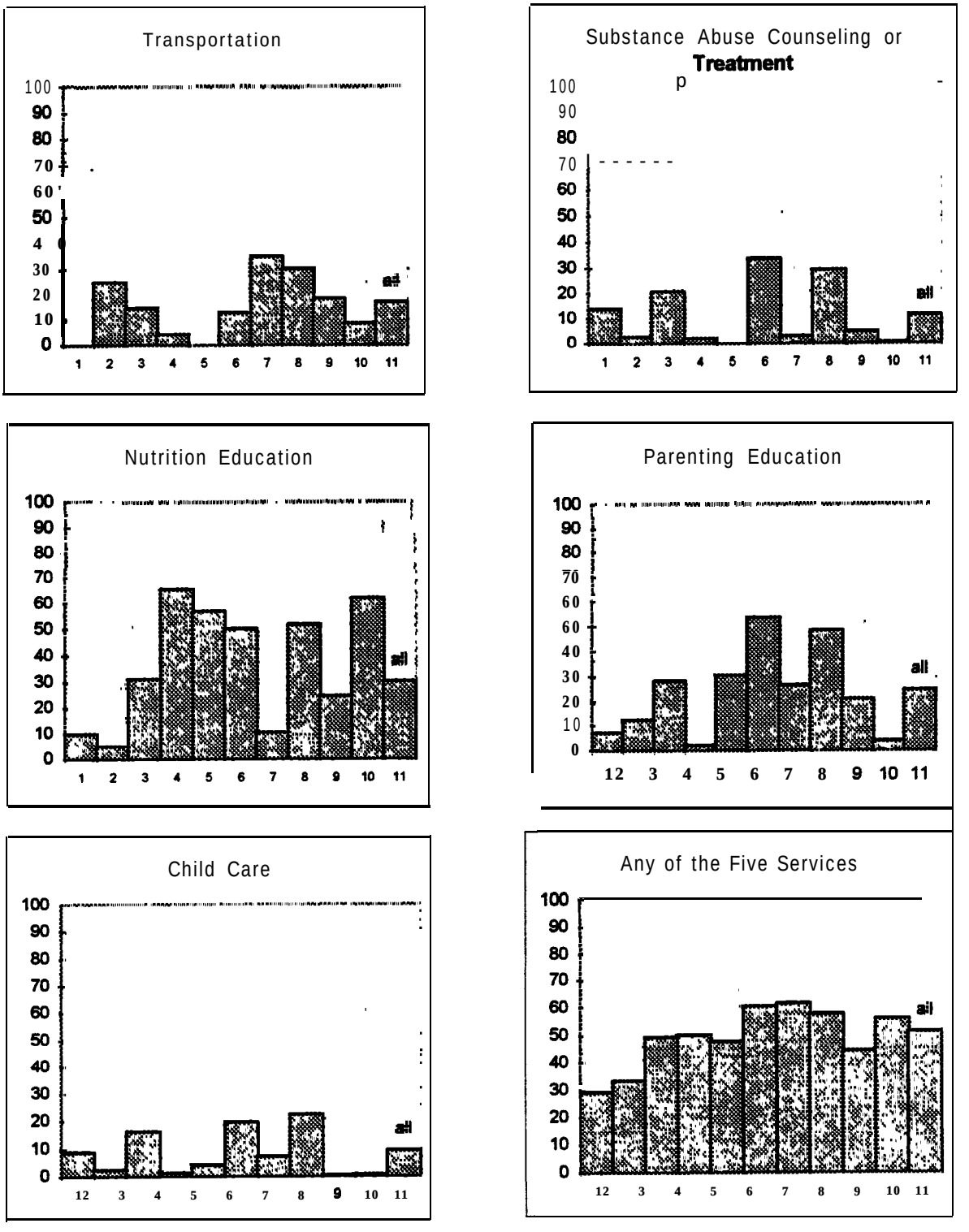
The Healthy Start projects funded a wide range of support services. Indeed, those services formed the core of much of the Healthy Start-funded activity in many projects. There are relatively complete client-level data for most projects for the following services: transportation, substance abuse counseling and treatment, nutrition education, parenting education, and child care. Figure IV.2 shows the percentage of clients receiving services from the 10 projects that reported client-level data on these five support services. (The other four projects' MDS files were missing large amounts of data on support services and are therefore excluded from the figures.)

a. Transportation

Most Healthy Start projects provided some transportation to appointments to reduce an often formidable barrier to service, although the percentage of clients receiving transportation was

FIGURE IV.2

PERCENT OF MATERNAL CLIENTS RECEIVING
HEALTHY START SUPPORT



1 Baltimore; 2 Birmingham; 3 Boston; 4 Detroit; 5 DC; 6 New York; 7 NW Indiana; 8 Oakland; 9 Philadelphia; 10 Pittsburgh

relatively low in most projects, ranging from no clients to about 35 percent of clients receiving such services. Transportation was particularly needed in some of the nonurban or rural areas (for example, parts of Northwest Indiana and the Pee Dee region) where public transportation was scarce.

The types of transportation services varied from project to project. Eight projects provided transportation directly, generally through a "baby van" owned by the project or by contracting for the service. A mother could call for a reservation or the van might circle Healthy Start neighborhoods regularly. Some projects also passed out transportation vouchers for the existing public transportation system. Generally, the O/CM workers decided when a voucher was needed.

b. Substance Abuse Counseling and Treatment

Problems associated with substance abuse were especially prevalent in Healthy Start areas, affecting the lives of Healthy Start clients in several ways. They or their family members or friends might have been substance abusers, or they might have been exposed to violence related to substance use. The range and complexity of these experiences underscored the great need for substance abuse services in Healthy Start communities.

Substance abuse interventions were used by most Healthy Start projects, although the form of the intervention varied greatly, and the number of clients receiving services was small (about 10 percent of clients across the 10 projects with data). Some projects made special arrangements for "slots" in treatment programs, whereby Healthy Start clients received priority for admission. Other projects had a special outreach and referral process for substance-abusing women that was integrated with the project's O/CM efforts for all women. These projects either gave special training to O/CM workers, or they co-located specialists with those workers. Some projects continue to have

substantial difficulty finding adequate treatment programs, since the supply of substance abuse treatment remains inadequate in some Healthy Start communities.

c. Nutrition Education

Nutrition education was the most common support service for which we have client-level data. All Healthy Start projects developed one or more approaches to providing nutrition education. Most projects closely coordinated nutrition education with the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), which has an extensive nutrition education component. The educational materials used in these programs varied, but most projects covered the importance of a healthy lifestyle (e.g., the impact of smoking and substance abuse) as well as proper nutrition.

Nine projects integrated nutrition initiatives with O/CM efforts, often stationing O/CM workers at Healthy Start outreach centers to conduct nutrition education classes. Other projects (for example, Detroit and the District of Columbia) hired professional health educators to travel around the project area to give classes.

d. Parenting Education

Another relatively common support service was parenting education. As shown in Figure IV.2, about 20 percent of clients received this service in the 10 projects reporting data. Many of the young parents enrolled in Healthy Start had little parenting experience, and other Healthy Start families had experienced or were at risk of experiencing family violence. Consequently, most projects established some kind of parenting education, which was often closely coordinated with other one-on-one educational efforts such as nutrition education. Like nutrition education, parenting education took place either in classes held at central sites or in a more decentralized manner such as during home

visits. Other projects, such as Boston, funded special programs in which parent mentors helped new parents.

e. Child Care

While child care was not a very common Healthy Start support service (with less than 10 percent of clients receiving this service), it was offered on a limited basis by most projects. Some projects made arrangements for temporary child care in emergency situations. Other projects had more routine child care arrangements, like Oakland where child care workers were hired to care for children on a drop-in basis when clients attended classes. Baltimore, New York, and Northwest Indiana added "tot areas" where children could play during their parents' prenatal care visits. (Data on children served by such centers are not included in the client-level MDS, and so are not shown in Figure IV.2.)

f. Other Support Services

Other support services offered by Healthy Start projects included literacy training; employment and training services oriented toward developing self-sufficiency; housing assistance; food, clothing, or other emergency assistance; mental health services; grief counseling; a variety of services of the above types targeted to the male partners of Healthy Start clients; adolescent education and empowerment programs; and a variety of other diverse services. There are no consistent client-level data across projects to quantify the number of individuals who received these services, but it seems likely that at least an additional 20 percent of Healthy Start maternal clients (as well as numerous other individuals such as adolescents and male partners) received services of this type funded by Healthy Start. The services for male partners were particularly interesting and innovative in some

projects. Local evaluations provide additional information on this topic, and Brindis (1996) describes adolescent services funded under Healthy Start.

3. Enhancements to Clinical Services

All Healthy Start projects provided, either directly or through contracts, a wide range of clinic services to infants and pregnant women. Many of the traditional clinic facilities in Healthy Start areas were deteriorating and overcrowded. For several reasons, Healthy Start projects modified or extended this delivery system for prenatal, postpartum, and **infant care** rather than developing new facilities:

- Most Healthy Start projects had inadequate financial resources to begin the ambitious task of developing an optimum primary health care delivery system.
- Most projects concluded that it would be wasteful to duplicate the existing clinical service delivery systems.
- In a competitive health care delivery environment, existing providers were naturally resistant to the development of a new delivery system.
- The short time period of the demonstration and the perceived need to improve access and support services led to a nonclinical emphasis in most projects.

Because of the number of delivery sites and the complexity of the interventions, we classified the clinical services by type (prenatal/postpartum/infant care or family planning) and in Table IV.3 show whether each project funded a particular type of service. Across all projects, over 160 care delivery sites received some Healthy Start funds. However, the average grant to each delivery site was small-about **$75,000--although** there was substantial variation across projects. Larger grants were given in places like Northwest Indiana and Oakland where projects established "one-stop shopping centers" and where clinical services were provided in conjunction with other Healthy Start

TABLE IV.3

HEALTHY START FUNDED CLINICAL PROVIDERS

Project	Number of Clinical Providers Funded by Healthy Start: Prenatal/ Post-partum and Infant Care	Family Planning	Total	Expenditures in FY96 for Clinical Services ($1,000s): Total	Average per Provider
Baltimore	12	2	14	$1,437	$103
Birmingham	1	6	7	534	76
Boston	0	0	0	0	0
Chicago	9	7	16	1,879	117
Cleveland	0	3	3	156	52
Detroit	4	1	5	648	130
DC	8	3	11	1,321	120
New Orleans	5	3	8	1,226	153
N.W. Indiana	3	0	3	569	189
New York	17	9	26	382	15
Oakland	7	7	14	2,213	158
Pee Dee	13	9	22	944	43
Philadelphia	12	10	22	1,072	49
Pittsburgh	9	6	15	109	7
Total	**100**	**66**	**166**	**$12,418**	**$75**

SOURCE: Number of providers: Site visits, January-March 1996.
Expenditures: Special FY96 expenditure report prepared by projects in late 1996.

NOTE: Some providers offer both types of services and are counted in both categories.

services.' Many projects are hoping that after federal funding for Healthy Start is discontinued, funding from other federal, state, and local sources (through 330 Community Health Center grants and Medicaid, in particular) may be available to continue and expand some of the system-wide changes in clinical care initiated under the program.

4. **Service Integration and Coordination**

Healthy Start operated within very complex service delivery systems. One goal of Healthy Start was to encourage the development of systems of care by integrating prenatal, postpartum, and infant clinical and support services. Table IV.4 shows the large number of providers (contracted or referral) in each of the Healthy Start networks by type of service provided. Close to 700 providers were funded by 14 projects, and over 800 other providers were in the referral networks of the projects.6 Coordinating across such a large and diverse network of providers was a great challenge, and it is natural that the Healthy Start-funded services were more closely linked than nonfunded services.

Projects approached this challenge in several ways. First, they created service delivery networks to improve linkages between maternal and child health services. These networks were developed either through consortium membership, through formal referral arrangements (although these were quite rare), or through informal referral patterns that were encouraged and enhanced by the Healthy Start O/CM process. Second, as mentioned above, a few projects coordinated services through co-location. These one-stop shopping sites included some services that were funded by Healthy Start and some that were not. Third, some projects approached service coordination through improved

[5] Healthy Start funds cannot be used for major capital improvements; they can be used to make interior renovations to enhance existing facilities.

[6] See our second annual report (Devaney et al. 1996) for a complete inventory of these providers.

TABLE IV.4

NUMBER OF PROVIDER SITES IN THE HEALTHY START NETWORK, BY TYPE OF SERVICE AND FUNDING SOURCE

			Support Services															
	Clinical Services		Transportation		Substance Abuse Counseling and Treatment		Mental Health Services		Health and Nutrition Education		Male Partner Programs		Youth Initiatives		Other		Total	
Project	HS	Not HS	HS	Not HS	HS	Not HS	HS	Not HS	HS	Not HS	HS	Not HS	HS	Not HS	HS	Not HS	HS	Not HS
Baltimore	14	4	2	1	4	46	0	7	13	21	2	0	3	8	17	14	55	101
Birmingham	7	9	3	4	1	2	0	4	7	8	1	0	4	4	1	10	24	41
Boston	0	11	12	0	3	0	1	0	22	0	2	0	5	0	14	1	59	12
Chicago	16	12	5	1	9	2	0	0	7	4	0	2	5	2	17	21	59	44
Cleveland	3	13	3	4	2	23	2	7	2	12	1	2	22	4	1	41	36	106
Detroit	5	8	1	1	1	5	1	0	8	7	0	0	2	6	6	1	24	2x
D.C.	11	11	4	0	5	5	1	0	6	2	1	1	5	3	5	3	38	25
New Orleans	8	10	2	0	2	2	1	0	1	1	1	0	5	1	1	9	21	23
N. W. Indiana	3	10	3	1	4	5	0	5	6	3	0	0	3	4	6	6	25	34
New York	26	85	6	0	12	23	2	9	12	11	4	14	11	18	24	13	97	173
Oakland	14	18	2	0	5	3	4	1	5	Y	5	1	5	2	5	5	45	39
Pee Dee	22	19	12	0	12	7	1	3	11	7	7	0	7	4	6	20	80	60
Philadelphia	22	4	3	2	2	17	7	2	11	8	2	0	5	0	4	27	56	60
Pittsburgh	15	43	2	0	8	3	3	1	16	10	2	0	7	0	26	6	79	63
Total	**166**	**257**	**60**	**14**	**70**	**143**	**23**	**39**	129	**103**	28	**20**	a9	**56**	133	**177**	**698**	**809**

SOURCE: Site visits, January • March, 1996.

Note: Some providers offer services in multiple categories and are counted in each category.

HS: Healthy Start funded providers.
Not HS: Providers not funded by Healthy Start.

data linkages, although this was usually more a goal than a reality due to the difficulties in implementing a uniform data system.

5. Centralization of Services

Some projects chose to centralize the delivery of services and some chose a very decentralized approach. For example, one Healthy Start project had a highly centralized model of service delivery (Baltimore). Almost all services were delivered in two sites in that project, using common protocols. In contrast, the most diffuse models, such as those in Boston and Philadelphia, a very large number of providers and sites were used, generally through contracts with large numbers of community-based organizations. Both models successfully enhanced the service delivery system for low-income women and infants. However, the centralized model is easier to evaluate since it is easier to identify Healthy Start clients and to determine Healthy Start's unique contribution to changes in infant mortality and maternal and child health in the limited geographic area served by the project.

C. CLIENT AND PROVIDER PERCEPTIONS OF HEALTHY START SERVICES

Qualitative information on Healthy Start services came from our client and provider focus groups. The six key themes that emerged from the focus groups are discussed below.

1. Community Workers Were Key to Outreach

Many of the projects used community residents to conduct outreach and related support services. Both clients and providers viewed these outreach staff as critical to Healthy Start's success, especially in identifying clients who were considered harder to reach. Comments of focus group participants include the following:

The outreach workers are more like counselors. They talk to you about a lot of different things. If you have questions about anything, they 'll sit down and talk to you and explain it to you if you don 't understand. (client)

Even if they [outreach workers] can 't provide what it is you need they make it their business to try and get in contact with other organizations or programs...they check on you and let you know they're there for you if you need them. (client)

[Outreach workers]...have a tremendous interface role where they can (and correctly do) say to us 'Boy do you stink You're unfriendly, you're not available on the phone, you make us wait too long. I spend all this energy getting somebody who doesn't want to be there anyway to come in, and in five minutes you turn them off, and I've spent two hours getting them ready.' **Those** *are imperative messages--it's the only way we change the system... (provider)*

[Our peer outreach workers are] kids who were gang people and [were] serious at-risk kids. We trained them to go back and be peers, which is working out perfectly because they can go back to their neighborhoods and they can really talk to the kids better than we can. They're allowed to go into some of the areas that other providers really can't go into....Healthy Start has a good reputation in the community now. (provider)

Outreach staff often served as advocates for clients, helping them to obtain services and better treatment from welfare and other social service agencies.

In addition to other services, one great need is for advocacy services-particularly for clients who find it intimidating to deal with agencies such as the Department of Social Services. Because these clients are young and for the most part uneducated the providers [outreach workers] assist them not only by educating them about services but also by attending court hearings and doctors appointments with them. This ensures better quality of care and increases client confidence. (provider)

Although the majority of comments about the outreach workers were positive, some clients felt their **outreach workers were not as supportive, or that they sometimes went too far in trying to be helpful.**

I really didn 't come into the program needing a whole lot. She (counselor) was trying to be helpful, but she should stress independence rather than dependence. (client)

It 's like she (the social worker) wants to come in and be my mother. When you are talking and she disagrees...she wants to cut you off. I try to let her know that 'you are in my house and you are going to respect me regardless of what your title is. ' (client)

2. Healthy Start Improved Client Self-Esteem

Clients and providers noted that Healthy Start staff made a big impact on client self-esteem, providing the skills and support to help them believe in themselves and get their lives on track. This feeling of power and hope extended from the individuals to the community, helping to foster a positive attitude about the ability of individuals to make a difference in their communities.

> *They motivated me to be my own person. They helped me to come out and open up. To share how I really feel. And to not be ashamed about where I come from. They gave me a lot of self-esteem and motivated me to do the right thing and get a job. (client).*

> *They (counselors) approached me and told me I was going to need my diploma to make it in this society. I decided to go back andfinish. Now, if I see somebody dropping out,, I try and give them the same thing they gave me. (client)*

> *i&sense of the project is that it has marketed hope. A lot of times communities andpeople did not have hope. It's a reatty good social marketing strategy to give residents a voice...so we can be hopeful that we can really change this problem in our city. (provider)*

> *When they walk in the door they see African American images on the walls....a sense of cultural identity...a place where they feel 'this is for me '...and they may spend an extra 30 minutes there...it instills a sense of self worth, of pride...In order to heat the African American community, we have to honor our community, and that's what they feel when they come in and see the images. (provider)*

3. Healthy Start Improved Access to and Coordination of Services

Clients and providers believed that project efforts to improve access to services, and coordination and collaboration among providers seemed to work. Some projects heavily emphasized a "one-stop-shopping" approach, which was viewed as particularly helpful for the typical Healthy Start client who had to navigate a large and complicated service system:

> *I would have to go to a tot of different organizations to get everything that Healthy Start offers. A lot of running around. It is all wrapped up in one. You go to one place and find a tot of things. (client)*

We have truly linked case management and the medical piece, and that's something that was not in place before Healthy Start. The mom can come to one place and get everything, and that's what we were seeking to do in the inception-the one stop shopping. (provider)

For many of these moms, they're juggling so many things that unless it's much more of one-stop shopping for them, it's not going to happen for them or their children. (provider)

Many providers also commented on Healthy Start's role in strengthening ties among providers and in fostering coordination and collaboration. Healthy Start provided the issue-fighting infant mortality-that galvanized provider support, spurring them to improve referral networks and to somewhat reduce the competition and fragmentation among them.

We legitimize partnering and competition [among providers] at the same time. We 're not going to get rid of the competition. We 're foolish to try. But what we want to say at this level is 'this will help us all.' (provider)

Other entities have their own agenda, whereas Healthy Start has infant mortality as its agenda and it continues to motivate people to focus on the issues. (provider)

Before Healthy Start, there weren't a lot of places to refer women and there was no coordination. (provider)

This collaboration and coordination was thought to improve the care received by clients. Instead of each provider playing a limited and circumscribed role in the client's care, the strengthened provider network enabled providers to work together and coordinate care across settings and over time.

We've seen fewer walk-in deliveries into the ER, which has really been a step in the right direction. They 're getting earlier care. (provider)

Healthy Start has provided continuity of care, between in- and outpatient. We don't lose them because we are able to have home health nurses and discharge planners....Their health care provider has been able to get into the home and that's where things are really working. Home visits have helped with the parenting and helped decrease the morbidity

and mortality because they were able to put their hands on the problem, right then and there, at the home. (provider)

4. **Healthy Start Provided Caring Services**

Clients and providers repeatedly praised the caring and helpful Healthy Start approach, attributing much of the project's success to this kinder and more compassionate style.

One of the things I try to convey...is that the staff are very hind and sincere, understanding and loving. I just really want them to get a sense that you're not just going to an agency with 'professionals.' (provider)

We have to meet people where they are and they have to feel comfortable with where they are to bring them forward from there....Healthy Start is not just about providing services, but [about] serving the people where they are, and that has made a big, big, difference.... You wouldn't have any hind of impact if they didn't feel they could identify with you. (provider)

Clients contrasted the genuine and personal nature of the Healthy Start approach with the negative attitudes and the nature of services of some other providers in their community, particularly social services agencies.

Most of the time when you show somebody that you are concerned about them, they tend to become concerned about themselves....Now that those services are being offered, people are more receptive to the program. (client)

. . . this was a place I could go and feel comfortable. I was in a teenage group and even other people who were getting counseled were all sympathetic to me. (client)

With Healthy Start it was amazing. They were like a friend. They wouldjust give and give and try to find out all this information for you. They didn't want anything in exchange. They just wanted to be there for you. (client)

I was going to the health clinic....They would give me a checkup....the gynecologist would give me packages of condoms and stuff. That's it. There was no talking. There was no lessons. They didn't even teach you about breast feeding. (client)

[At the local public hospital] you go there for an appointment and there are a million other women in line for the services. The doctors are slow and you get a lot of residents. I

understand it's a teaching hospital, but [they make you feel] like cattle. You get branded and you go. It's a miserable experience. It really is. (client)

This last client added that, in Healthy Start, she was able to see one doctor throughout her pregnancy, receiving much more emotional and other kinds of support.

5. **Healthy Start Could Not Break Through All Personal and Environmental Barriers**

It has been somewhat difficult for Healthy Start to break through barriers related to a client's upbringing, lifestyle, and a sometimes hostile home or social environment. Fears about the child welfare system or immigration services, for example, were cited as reasons for resistance to Healthy Start services.

...it's a tough environment. You're trying to survive as opposed to trying to choose...am I going to eat tomorrow? Am I going to have something to wear? Am I going to have housing? Is my kid going to get beat up? So there's a reactive, immediate crisis always present. (provider)

You sometimes have a lot to fight against. You can't change the way a person was raised. You can't change their natural instinct to do the same thing to their child that was done to them, but you can make them aware of their behavior and how to do it differently, and you can help them find resources to help them when they're at a crisis point. (provider)

6. **Some Aspects of Healthy Start Needed Improvement**

Some providers expressed concern about inadequate training and support for outreach staff, and others felt the outreach workers should communicate more with appropriate medical and social service providers in the community.

The outreach workers' training should be enhanced and their morale lifted.... Training and morale play a big part in making the program successful. (provider)

Providers in several projects would like to see better cooperation and collaboration between themselves and other providers in the community.

> *I would like to see more communication between Healthy Start and the existing providers, because sometimes when you get a new program and you bring it into another program that's doing the same thing, people feel threatened. They want to protect their turf They think you're coming in to push them out, so they need to try and communicate with existing programs in the beginning more and continue so we feel it's just another arm of extended service. (provider)*

One project has struggled to involve churches in Healthy Start.

> *It has been very, very hard to penetrate into the churches....It's 'If you don't go to my church, I'm not going to help.' (provider)*

Many providers complained about the excessive administrative burden associated with data collection. They viewed time spent on this activity as time diverted from service provision.

> *We are direct service delivery providers. What the information system has done is taken away from direct services because now the case manager spends far too much time inputting data....They cannot interact as much, or have not been able to, with the clients because they are also required to spend a certain portion of their time inputting this information.... (provider)*

> *We spent tons of time in meetings as the health department staff were trying to develop data forms to do program evaluation. It was time consuming...and we had to actually be exemptedfrom the main reporting system because our program is so different...it took a lot of hours of negotiation. (provider)*

Many of the suggestions about ways to improve Healthy Start focused on how the program could be expanded or enhanced to reach a greater number of clients. Most of the projects struggled to involve male partners and family members, and providers believed that this component could be enhanced by increasing the focus on jobs and helping men to be productive members of the family and community.

*Health **providers** sometimes don't even understand how to involve men...the whole issue of reproductive health has been **very** female-based **(provider)***

*I see a strong connection between economic development and male involvement because men don't want to just go to parenting **classes....It's** about developing male identity and getting jobs where they can be head of the household and leaders in their community. **(provider)***

Focus group participants thought that Healthy Start eligibility guidelines could be improved because they restricted project services to residents in certain geographic areas or to certain ages. And other participants believed that projects could be improved by directing more attention to substance abuse problems, expanding the number of medical providers willing to serve low-income persons, adding recreational programs and more outreach for adolescents, and adding services for women and men in prison.

V. OTHER HEALTHY START INTERVENTIONS

The Healthy Start design had unique components in its focus on changing systems of care in the communities serving low-income, high-risk women and their families. As a result, many components of Healthy Start went beyond providing direct services and included activities to inform the public, as well as to study and report on problems associated with infant mortality. In addition to administration, consortium development, and direct service delivery, Healthy Start launched interventions in public information, management information systems, infant mortality review, and local evaluation.

A. PUBLIC INFORMATION

The Healthy Start demonstration featured both national and local public information components. The purpose of public information was threefold:

- To increase awareness in the community (consumers, providers, businesses) about the presence and adverse impact of infant mortality in their community
- To elicit community interest and participation in the local Healthy Start project
- To promote healthy behaviors among women of childbearing age

At the national level, Healthy Start conducted three waves of public information and education campaigns using national television, radio, posters, and billboards. For example, the third wave of public service advertisements, released in February 1997, urged women to avoid putting their babies' health "on the line" by seeking early and regular prenatal care. The campaign featured toll-free numbers for English- and Spanish-speaking callers.

HRSA contracted with Vanguard Communications, a Washington, DC-based small business, to assist with the national campaign and to provide technical assistance to each project in planning and implementing their public information program. Vanguard also organized regular telephone conference calls and published a newsletter to help projects share their ideas.

At the local level, each of the Healthy Start projects implemented programs to promote prenatal care and encourage the use of services. Projects used a mixture of strategies, such as local television and radio public service announcements, newsletters, and other educational materials. As shown in Table V.l, several components of the public information programs were used in most projects, including media campaigns, brochures, newsletters, and hotlines. Additional components that were not as common or that were more variable included special interagency referral efforts, provider outreach and education, and community-wide health education and promotion. The following efforts exemplify the great variety of Healthy Start public information initiatives:

- Projects issued press releases and organized "media events" to reach local newspapers. For example, New York had a kick-off event at City Hall attended by the mayor.
- Boston convened lunch meetings with broadcast and print journalists to raise the awareness of Healthy Start. The project also funded a cable television health affairs reporter.
- The District of Columbia sponsored a poster contest for local high school students. The posters, which were to contain healthy life style messages, were displayed at a city office building and judged by local artists. The kick-off for the exhibit was covered by the press, and the posters were also displayed at Healthy Start community meetings.
- Community youth in Philadelphia created and produced a play and a rap video about adolescent pregnancy.
- Projects sent representatives to community events such as local health fairs to distribute brochures and publicize Healthy Start.

TABLE V. 1

HEALTHY START PUBLIC INFORMATION STRATEGIES

Site	Media Campaigns		Brochures	Newsletters		Hot Lines		
	Radio/TV	Posters/ Billboards		At Least Quarterly	Less than Quarterly	Healthy Start Funds	Partial HS funds	Other funds
Baltimore	✓	✓	✓	✓				✓ (State)
Birmingham	✓	✓	✓	✓		✓		
Boston	✓	✓	✓	✓			✓	
Chicago	✓	✓	✓					✓ (State)
Cleveland	✓	✓	✓	✓		✓		✓ (State)
Detroit			✓	✓				✓ (County)
DC	✓	✓	✓	✓			✓	
New Orleans	✓	✓	✓	✓				✓ (State)
New York	✓	✓	✓		✓			✓ (City)
N.W. Indiana	✓	✓	✓	✓		✓		
Oakland	✓	✓	✓	✓		✓		
Pee Dee	✓	✓	✓		✓	✓		
Philadelphia	✓	✓	✓	✓			✓	
Pittsburgh	✓	✓	✓		✓	✓		✓ (State)
Total Sites	13	13	14	10		6	3	7

SOURCE: Site visits, January - March 1996 and telephone updates, May - June 1997.

- Cleveland held a graduation ceremony for enrolled infants reaching their first birthday. Local print and electronic media covered the event.
- The Fanners Market, started by Healthy Start in New York, disseminated nutrition information, brought fresh produce into the community, and provided some community and economic development opportunities.
- Pittsburgh sponsored "Healthy Start Sundays" in area churches where project activities were publicized.
- The vehicles that provided Healthy Start transportation services in some communities (e.g., the District of Columbia, Northwest Indiana, and Philadelphia) displayed the names, logos, and hot line telephone numbers for Healthy Start projects.
- Gifts (provided, for example, at enrollment) often carried the project name or logo into the community.

The public information activities of Healthy Start were some of the most innovative and interesting of all project efforts, and site visitors ranked most projects highly on these efforts. The breadth of these public information campaigns distinguish Healthy Start from previous major maternal and child health demonstration projects.

B. MANAGEMENT INFORMATION SYSTEMS

Healthy Start projects received funding to develop a dual-purpose management information system that would (1) improve internal management (e.g., oversight of subcontractors and monitoring interim performance objectives) and **(2)** meet federal reporting requirements for providing data to the Division of Healthy Start and the national evaluation. These systems were expensive, with the 14 projects together spending about $6 million in fiscal year 1996 alone on their systems.

The specifications for the Minimum Data Set (MDS) that was to be collected by each project and submitted to the national evaluation were developed under contract with Lewin/VHI and its

subcontractor MDS Associates, as part of the development of the design for the national evaluation. After the development of the draft data set, HRSA solicited and received comments on the database design. Some of the initial feedback, particularly from project staff, led to revising the definition of "client" and to providing additional instructions on data submission procedures (Raykovich et al. 1996). After receiving comments, HRSA proceeded to require submission of the full data set on all maternal and infant clients. There was a strong feeling that, with a program as large as Healthy Start, the collection of client-level data was necessary for program accountability.

All projects struggled to implement a system that met HRSA requirements for the MDS, in part, because of the volume of information in the data set. The MDS included an extensive maternal data set that included 241 variables on 12 topics as follows:

- Characteristics of client
- Key dates of services and providers
- Pregnancy history
- Medical risk factors
- Behavioral risk factors
- Prenatal care
- Psychosocial services
- Scope and content of case management/facilitating services
- Individual development services
- Psychosocial and supportive services; other family members
- Delivery
- Postpartum care

Furthermore, an additional 159 variables on the following 8 other topics were required for the infant record: demographic characteristics; characteristics at birth, health status at first pediatric visit and at age one; use of medical services; use of psychosocial support services, facilitating services, and individual development services; and mortality data.

Overall, most Healthy Start projects were not successful at developing a functioning management information system and providing complete MDS data. Although the national evaluation team supplied a series of technical feedback reports on the quality of the MDS data, projects have not yet submitted data sets containing all required variables for any time period. Several factors impeded the successful development of the management information systems. Given that no site succeeded entirely, we can conclude that these factors were overarching as well as site-specific.

The reasons for not submitting complete data sets are varied. One common problem was that the projects were generally not in a position to directly collect much of the required data, particularly the clinical data. For example, clinical services were, in almost all cases, contracted or available to clients though an existing provider system. The Healthy Start contract was a small part of the funding for those providers, who consequently had little incentive to comply with burdensome data collection requirements. Even in the District of Columbia, for example, which developed a sophisticated data system (DCMOMS) and supplied free hardware and software to providers, all variables were not entered consistently into the system.

Some projects developed case management systems that provided excellent data on case management encounters but did not provide accurate information on other support services. Projects building on such a case management system to collect the MDS had problems with data quality

because case managers did not always have reliable information on support services and clinical services.

One important factor affecting the development of the MDS was that, when the specifications for the MDS were developed, there was still some question about which types of provider organizations would be providing data to the grantees. The data set included a large number of clinical variables (e.g., maternal clinical risk factors and conditions, clinical services) that most service delivery sites were unable to provide. Consequently, the creation of the very large data set generally required merging data from multiple sources. For most projects, the task of successfully obtaining and merging several different types of data on an ongoing basis caused delays in the implementation of their MDS and has hindered their ability to fully comply with MDS specifications.

Another factor impeding development was the lack of senior expertise in systems development at the federal and project level early in the design of the MDS specifications, which took place before the contract for the national evaluation was awarded. If such expertise had existed early on, closer collaboration between federal and local staff (and the national evaluator, once on board) might have forged a compromise approach to data collection that would have been more feasible, given the actual structure of the demonstrations. However, this should have occurred very early in the demonstration-before the MDS specifications were finalized-since once they were released, some projects took costly steps to implement them, creating pressure not to change requirements. It would have been easier to drop variables from the data set than to add them, and condensing the data set was one of the steps that might have increased feasibility. However, even when a set of "priority" variables was identified, projects still had difficulty complying with MDS reporting requirements for those variables.

Another major impediment to system development was the absence of strict data collection and processing requirements. There were neither standard forms for data collection nor standard definitions for where data should be captured (e.g., from the medical record, from vital statistics, or from interviews with program clients or providers). This led to a lack of comparability across projects and over time for many key variables (e.g., maternal risk factors, infant immunizations); consequently, such data are not useful for program evaluation or monitoring. In retrospect, it appears that it would have been preferable to develop standard data collection protocols and a data processing software package for projects to use from the beginning of the demonstration. However, this would have been very difficult, given the diversity of Healthy Start programs and the lack of knowledge about who the actual providers would be when the data set was developed. A very simple data set that could be used to identify clients and to obtain simple demographic characteristics and service data was probably all that was feasible. In the end, after large expenditures and much frustration, this small data set is what is now available for cross-site evaluation.

Some projects wanted to use the Healthy Start MDS as a springboard to developing a broader data system that could be used to monitor maternal and child health programs during and after Healthy Start. There is nothing inherently flawed with such an approach, and funding this effort through Healthy Start was supported by MCH advocacy groups. However, combining the two efforts (implementing a system-wide data collection and processing system, and collecting evaluation data) proved extremely difficult. In Chicago, the difficulties and complexities of the system-wide effort took precedence over collecting evaluation data. The Chicago data system development was still not complete when this report was prepared. In the future, the goals and methods for these two types of efforts should be clearly specified and distinguished from one another.

Given these problems, it is not surprising that so many of the projects had problems developing fully functioning management information systems according to the MDS specifications, despite considerable and sustained effort by HRSA and project staff. It is important to note that, at the time of this writing, projects are continuing to work to improve their data systems, and HRSA continues to provide some technical assistance to them.[1] While the results of their continued efforts may not provide data for the national evaluation, they may provide some useful feedback to projects as they look to the future of monitoring and sustaining their programs.

C. INFANT MORTALITY REVIEW[2]

Infant mortality review (IMR) programs were designed to assist projects in identifying the factors affecting infant mortality in their area. In this program component, infant deaths were reviewed by committees to (1) determine the clinical, social, and health factors contributing to an individual death and (2) make recommendations to improve infant outcomes.

Core IMR objectives across all projects focused on identifying factors leading to infant mortality, although there was variation in the complexity and orientation of the review process across projects. Most had a two-tiered structure consisting of a technical review panel, which conducted a more medically oriented review, and a community panel, which provided a social focus. The material presented to the panels consisted of summaries of data derived from abstraction of medical records, social services records, coroner's and autopsy reports, police reports, and health department records. With varying degrees of success, all but one project attempted to interview the mother.

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[1] The Division of Healthy Start contracted with the Mayatech Corporation in 1996 to assess the projects' management information systems and to provide needed technical assistance.

[2] See Baltay, McCormick, and Wise (1997) for a more in-depth discussion of the Healthy Start IMR process.

Barriers to implementation of the IMR included the difficulty of setting up an interview with the mother, problems implementing recommendations, timeliness of case identification for review, confidentiality concerns and access to medical records, variation in the level of interest among panelists, and lack of staff expertise with the IMR process. Facilitating factors included panelists' commitment and support from the local health department and medical society.

Projects varied in the extent to which they relied on quantitative and qualitative data to develop recommendations to improve infant outcomes. Some projects used a strictly qualitative approach and provided no data analysis to the review panel. Others attempted to incorporate epidemiological data into the case-by-case review process. These projects mainly used frequency distributions and trend data to augment the case-by-case review and facilitate the formulation of community-specific recommendations.

The Healthy Start projects disseminated recommendations resulting from the IMR process in several ways. The universal channel for dissemination was the membership of the two panels. The second most common channel was the Healthy Start consortium. Other methods included internal feedback to the Healthy Start project staff, presentations to the local medical community, and production of reports targeted to relevant community entities.

Productivity in the IMR process varied across projects, ranging from record abstraction for 14 percent through 100 percent of all infant deaths in the project area and maternal interviews for less than 1 percent through 79 percent of infant deaths. Likewise, projects varied in the total number of recommendations developed (0 to 40) and those fully implemented (0 to 25).

The Healthy Start IMR model has generally been appreciated by projects as a useful tool for characterizing their local causes of infant mortality. The IMR efforts have yielded valuable information and have helped in the development of meaningful policy recommendations for the

projects' communities. Project staff felt that the process also had some other positive spinoff effects. For example, they noted the opportunity to provide grief counseling through the maternal interviews.

Some problems were also identified:

- In general the review process was complex, with low capture rates.
- Maternal interviews were expensive and consequently a difficult-to-sustain component of the process. (As of August 1996, none of the projects had identified funding to continue such interviews.)
- The IMR process as implemented often did not provide a ready mechanism for prioritizing recommendations and implementing them.

D. LOCAL EVALUATION

HRSA did not mandate local evaluation, but all projects proposed approaches to evaluating their programs. As stated in HRSA *Guidance* to grantees, projects were encouraged "to develop local evaluations that would provide timely feedback to project directors ... Local evaluations can be used for process and outcome analyses of unique components of a project's intervention .... Local evaluations are not to duplicate the responsibilities of the national evaluation. ..."

Table V.2 shows that all of the 14 projects had some form of local evaluation. While each project spent a modest amount on local evaluation in any given year (from $24 thousand to $377 thousand in fiscal year 1996), the overall cost of local evaluation was relatively high, substantially more than the national evaluation. These 14 projects together spent about $2.5 million in fiscal year 1996 on local evaluations. The table shows that the projects employed two kinds of local evaluators: faculty of local universities (employed by 11 projects) and staff internal to the project. Consortia members and project staff generally participated in some manner in local evaluations when their

TABLE V.2

HEALTHY START LOCAL EVALUATORS

Project	Evaluator	Internal	University
Baltimore	Dept. of Maternal and Child Health Johns Hopkins University (Patricia O'Campo)		✓
Birmingham	Dept. of Maternal and Child Health University of Alabama (Lorraine Klerman)		✓
Boston	Boston Division of Public Health (Blair Cohen)	✓	
Chicago	Center for Health Administration Studies University of Chicago (Kristiania Raube)		✓
Cleveland	Mandell School of Applied Social Services Case Western Reserve University (Darlyne Bailey)		✓
Detroit	Institute of Maternal and Child Health Wayne State University (Marilyn Poland Laken)		✓
DC	Social Work Research and Development Center Howard University (Feroz Ahmed)		✓
New Orleans	Biostatistics & Epidemiology Dept. Tulane School of Public Health and Tropical Medicine (Bill Ward, Fran Mather)		✓
New York	New York Healthy Start/MHRA Inc. (Cheryl Merzel)	✓	
NW Indiana	Purdue University/Calumet (C. Pat Obi)		✓
Oakland	Center for Reproductive Health Policy Research, University of California at San Francisco (Claire Brindis)		✓
Pee Dee	Institute for Families in Societies University of South Carolina (Arlene Bowers Andrews)		✓
Philadelphia	Office of MCH/Philadelphia Healthy Start City of Philadelphia, Dept. of Public Health (Jenny Culhane)	✓	
Pittsburgh	University of Pittsburgh (Christine Pistella and Ravi Sharma)		✓

NOTE: Table shows evaluators during the last demonstration year (name of evaluation director in parentheses).

project had an evaluation contract. The following partial list of completed reports exemplifies the great variety of local evaluations:

- "Baltimore City Healthy Start Program's Community Evaluation Report on Education, Employment and Family Planning"
- "Prenatal Care in the Birmingham Healthy Start Area, 1993"
- "The Boston Healthy Start Initiative: A Case Management Cost Analysis"
- "A Collaborative University-Community-Agency Model: the Chicago Healthy Start Initiative"
- "The DC Healthy Start Project: DC Maternal and Obstetrical Monitoring System (DCMOMS) Evaluation Report"
- "Community-Based Evaluation of Public Health Programs: Decision Making at the Local Level" (New York)
- "Informed Consent and Confidentiality: Dilemmas in Interagency Collaboration and Centralized Data Reporting" (Philadelphia)
- "Summary of Preliminary Findings from the 1995 Healthy Start Telephone Survey" (Pittsburgh)

HRSA's guidance suggested that local evaluations should focus on process issues, generating direct feedback that would assist projects in improving program operations, and as the above list of topics suggests, this was often the case. During our site visits, however, staff from many projects indicated that they had not obtained very useful ongoing feedback from their local evaluations. Similarly, some local evaluators expressed frustration at not being "heard" by local project staff and at not receiving timely data that would allow them to produce such feedback. However, there were notable exceptions to this pattern. For example, Baltimore staff was very explicit about their positive relationship with, and the important role of, their local evaluator. By executing the local evaluation contract early in the project period, Baltimore Healthy Start staff were able to ensure that

data collection efforts appropriate to the evaluation were in place and that evaluators developed channels for keeping the project staff informed of their findings.

Although projects were discouraged by HRSA from conducting evaluations that duplicated the outcomes analysis component of the national evaluation, there was local interest in demonstrating program impacts before such results were produced by the national evaluation. In more than one instance, reports of declines in infant mortality appeared in the local press. Given that Healthy Start focused on reducing infant mortality, and that consortia and project staff were substantially concerned with knowing whether and the extent to which they met their goals of reducing infant mortality by 50 percent, it is not surprising that the projects wanted their local evaluators to produce information on birth outcomes. However, there are many methodological issues that influence the study of birth outcomes (e.g., type of data, timeliness and completeness of data, comparison groups). Differences in methodology create the potential for conflicting results to emerge from local and national evaluations.

VI. SUSTAINING HEALTHY START

A. OVERVIEW

Sustaining Healthy Start activities became a major issue for all projects as the date for significant reductions in federal funding approached in the fall of 1997. As with other aspects of Healthy Start, plans to sustain program activities varied widely by project, as indicated in the telephone updates in mid-1997.

HRSA has helped projects address sustainability in several ways. As part of year six grant proposals to HRSA, each project was required to outline its program priorities. The Division of Healthy Start then provided technical assistance to projects about how to sustain priority activities. A technical assistance contractor (Mark Joffee) visited all Healthy Start projects and helped staff recognize and "package" those project components they felt were most marketable to outside entities. HRSA also addressed the issue of sustainability at the annual grantee meetings through speakers and special sessions.

As shown in Table VI. 1, projects implemented a mix of strategies to sustain some or all program components, including:

- Forming a nonprofit organization
- Integrating Healthy Start activities with health department activities
- Negotiating with managed care organizations or Medicaid programs to provide services
- Submitting grant applications to new funders such as foundations
- Giving technical assistance to their contractors to help them secure alternative funding

TABLE VI.1

PRIMARY SUSTAINABILITY STRATEGIES

Site	Forming a Non-Profit Organization	Integration with Health Department Activities	Managed Care Organization end Medicaid Negotiations	Grant Applications to New Funders	Technical Assistance to Contractors
Baltimore		✓	✓	✓	
Birmingham		✓		✓	✓
Boston	✓		✓	✓	✓
Chicago			✓		✓
Cleveland			✓		
Detroit		✓			
DC	✓		✓	✓	
New Orleans	✓				
New York			✓		
NW Indiana		✓	✓	✓	
Oakland		✓			✓
Pee Dee	✓	✓	✓	✓	
Philadelphia	Applying		✓	✓	
Pittsburgh			✓	✓	

SOURCE: Telephone follow-up updates in May-June, 1997.

Despite these efforts, all projects anticipated some decrease in their staff and their services. As a result, they took a hard look at their projects and made difficult decisions about which activities to eliminate. Some services were more likely to be sustained naturally through existing programs--clinical services covered by Medicaid is one example. These were often eliminated from the activities under consideration, allowing staff to focus on ways to fund the more difficult-to-sustain services. Projects also eliminated services not viewed as critical or holding little or no promise for being sustained. This too allowed staff to focus on services most likely to survive in the post-federal funding period.

B. APPROACHES TO SUSTAINABILITY BY PROGRAM COMPONENT

The following sections provide an overview of plans for sustaining the key Healthy Start components. As shown, these plans varied by type of component and by project.

1. Administration

Administrative staffwere usually hired specifically for the Healthy Start project. Consequently, restrictions in federal funding caused projects to re-examine each administrative staff position. Some staff who were employees of health departments-as in Baltimore, Detroit, and Philadelphia--had civil service status and retained their jobs, with the possibility that they might assume new responsibilities. Other Healthy Start staff became employees of the health department. In still other cases, projects sought new sources of revenue to cover administrative positions. For example, New Orleans hoped that third-party reimbursement for Healthy Start services would serve this purpose.

Despite these efforts, most projects initiated or anticipated administrative staff layoffs that would occur with the decreased funding in October 1997. The magnitude and timing of these changes was not yet clear at the time this report was prepared.

2. Consortium

HRSA planned to continue funding the central consortium in the smaller year 7 grants to the **14** projects, so plans to sustain this component were less developed than for other components. One approach to **sustaining** the consortium was to incorporate it as a separate nonprofit entity; five projects (Boston, DC, New Orleans, Pee Dee and Philadelphia) had done this or were in the process of doing so. Through incorporation, projects sought to develop a broader base of funding sources, since foundations, for example, might be reluctant to provide grants directly to a health department but willing to fund a nonprofit entity independent of the grantee agency. For example, the consortium in Boston received some funding from the Sunkist Foundation, and staffwere requesting additional support from the Fannie Mae Foundation.

Since the consortium had been a unique vehicle-bringing together providers, advocates, and consumers to focus on maternal and child health issues-a few projects hoped that the consortium members' interest in and commitment to Healthy Start would sustain the meetings regardless of funding. Baltimore, Birmingham, New York, and Northwest Indiana all hoped that the consortium would continue in this voluntary manner. However, without funding, there will be few staff to organize meetings and handle administrative issues, responsibilities that have been time consuming for most projects.

Local consortia organized through existing **CBOs** have the potential to be sustained by those organizations. In Cleveland, for example, the Healthy Start staff hope the local consortia will continue under the Neighborhood Centers Association. Similarly, because local consortia in Oakland and New York are standing committees of the contracting agencies, they are more likely to continue.

3. Outreach and Case Management

O/CM is the key Healthy Start component that projects would most like to sustain after federal funding is discontinued. One of the primary ways to do this is through contracting for reimbursement with managed care organizations (MCOs) or directly with Medicaid agencies. At the time of the telephone interviews, negotiations for reimbursement were occurring in Baltimore, Boston, Chicago, Cleveland, DC, New York, Northwest Indiana, Pee Dee, Philadelphia, and Pittsburgh. In DC, for example, Healthy Start had a contract with one MCO for services to children with special health care needs; negotiations for more general O/CM services were on hold because MCOs had not yet signed contracts with Medicaid.

When O/CM services were marketed to MCOs or state Medicaid agencies, the issue of a 'disconnect" between Healthy Start program objectives and those of MCOs and Medicaid agencies arose repeatedly. Primarily concerned with the recruitment of new members, MCOs often did not have a strong appreciation for the more holistic and socially focused services that evolved through Healthy Start. And Medicaid-reimbursed case management often has a clinical focus. It is still too early to determine whether these potential conflicts will persist and how they will be resolved once contracts are signed and implemented.

Another potential source of sustained funding for O/CM services was health departments. In Birmingham, for example, the health department planned to integrate Healthy Start outreach and health education into its clinics.

4. Other Support Services

While projects would like to sustain support services, such as health education, transportation, and child care, they have found it difficult to identify funding sources. A number of projects have

turned to private foundations for grant funds. In Oakland, Kaiser is helping to support _a transportation van. In Northwest Indiana, the Gary Foundation is a potential **funder** for child care services. Other projects have worked with their health departments to incorporate some Healthy Start support services into existing programs. However, several projects proposed to discontinue certain support services because it was too **difficult** to find funding to sustain them.

5. Clinical Services

Clinical services were more likely than O/CM or support services to be discontinued. The major reason given for this was that clinical services could potentially be funded through Medicaid and managed care plans. For example, Detroit Healthy Start scaled back the enhanced services it provided in city health department child and adolescent clinics. The DC project eliminated the perinatal services it provided at DC General Hospital, which will seek Medicaid funding for the sonography and other services for high-risk pregnant women once provided by Healthy Start. Philadelphia also discontinued clinical services under the assumption that they could soon be funded through managed care arrangements.

6. Management Information Systems, Infant Mortality Review, and Public Information

Despite the **difficulty** in implementing data systems, most projects were interested in **sustaining** their MIS beyond federal funding. A number of projects emphasized the need for such systems in human service organizations. In several locations, Healthy Start was the first such organization to attempt the development of a comprehensive data system. The projects administered by health departments hoped that the department would appreciate the value of the system and continue to fund it. Baltimore took another approach, incorporating the cost of its MIS into the service cost proposed to managed care organizations.

Most projects found that infant mortality review was a valuable and informative component of Healthy Start, and worth sustaining. Some projects hoped the health department would assume responsibility for IMR, potentially expanding beyond the Healthy Start target area. For example, in Northwest Indiana and Pee Dee, the state health department conducts its own IMR and will continue to cover the Healthy Start target area.

Although many projects implemented innovative public information strategies, this component appeared to be the most likely to be discontinued when federal funding for it ended. Many projects also learned that a targeted information dissemination strategy can be more effective a than broad-based campaign in reaching those most in need of Healthy Start services. A few projects mentioned potential collaborations that might sustain some public information efforts. Pittsburgh staff, for example, expressed hope that Healthy Start contractors would continue to support public information efforts.

C. SUMMARY

All Healthy Start projects expected a drop in federal funding and adopted one or more strategies for sustaining many of their Healthy Start activities. It seems apparent that much of the work of Healthy Start will continue through (1) federal funding for some components, (2) integration with existing health department activities, and (3) new sources of funding such as revenue from managed care plans and grants from foundation. It is too soon to tell whether this near-term continuation of much of the Healthy Start program will endure to provide a long-term legacy of the demonstration.

VII. CONCLUSIONS AND LESSONS

As the demonstration phase of Healthy Start comes to a close, it is possible to summarize some of the key lessons about implementing such a large, far-reaching program. The discussion in this chapter is an assessment by the site visitors of the major lessons that should be considered when conducting other demonstrations of similar scope. These lessons fall into the following categories:

- Community context and factors beyond the control of the demonstration program or its funders
- Project organization and administration
- Community involvement, including the consortium and community development
- Service delivery

In this discussion, the term "implementation success" does not imply success at reducing infant mortality, the ultimate outcome goal for the demonstration-data to measure this are not yet available. Rather, it means success at meeting interim process objectives such as hiring and retaining staff, and putting the planned program in place.

A. COMMUNITY CONTEXT

Each Healthy Start project developed within a community that grew along with the project. Some community factors facilitated, while others impeded, demonstration efforts to reduce infant mortality.

1. **Political support from community leaders, particularly the top leadership such as the mayor or governor, was important to successful implementation.**

The level of political involvement in Healthy Start signifies the extent to which the program is publicly recognized and supported. A high level of involvement provides Healthy Start with a strong base of support, publicly validating the project and increasing visibility. Consequently, political support can facilitate networking with other agencies (public and private), help garner state and local funding for Healthy Start activities, and increase the potential for sustainability when federal funding ends. Political figures can also be strong advocates for including Healthy Start in new programs or policies when they are being developed-Medicaid managed care and health department restructuring are two examples. Such political support facilitated implementation of some projects. In Cleveland, the mayor met regularly with demonstration staff, and in Oakland, several county supervisors were closely involved in project implementation and oversight.

On the other hand, a low level of political involvement can render program implementation and operation more challenging, as full responsibility for project visibility and integration with other government components falls to the projects. Also, strong political support is difficult to maintain--especially when other political crises divert the attention of an otherwise supportive political establishment. For example, the financial crisis in the District of Columbia, which spawned the formation of a control board, delayed or stopped payment for some Healthy Start contractors. Another reason such support is difficult to sustain is that, over the life of a long demonstration such as Healthy Start, political support may change dramatically with a change in administration. Seven of the 13 Healthy Start projects are located in cities that elected new mayors during the demonstration period.

Given the clear tie between political support and successful program implementation, it is important for leaders of other large federal demonstrations to stress the development and

maintenance of state and local political support for a program, especially when support is needed-to sustain activities after federal funding ends. Indeed, skills in developing such support should be one of the criteria for selecting project leaders, and it should be recognized from the beginning that this activity will absorb some of the project leadership's energy and time.

2. **Demographic, economic, and health care system changes in demonstration areas can affect demonstration success and are beyond the control of the program.**

While we did not observe dramatic shifts in population during the demonstration period, certain trends from the 1980s continued into the 1990s. These included the continued migration of middle class minority groups from cities to suburbs and the migration of immigrant groups into many Healthy Start project areas. The outmigration of middle class groups left a smaller and more disadvantaged population group in the Healthy Start service areas. This trend was reflected in a steady decline in births in the project area. Also, there were changes in local health care systems, including the implementation of Medicaid managed care in some areas, which may also have affected infant mortality in unmeasurable ways. It is difficult to control for these factors in our outcomes analysis, given the small number of demographic and contextual variables available to the national evaluation.

B. ORGANIZATION AND ADMINISTRATION

As with any large, complex program, the successful organization and administration of Healthy Start was extremely important. The extent to which projects were able to recruit and retain a strong staff (especially senior staff), develop and implement effective administrative procedures, and monitor the work of contractors made the difference between successful and less-than-successful implementation. As recipients of large federal grants, the projects had an urgent need to quickly develop an administrative structure in order to proceed 'with other aspects of the program.

1. **The speedy development of an administrative structure was facilitated by a combination of public and private, nonprofit administration.**

Three projects (Baltimore, New Orleans, and Pittsburgh) developed a nonprofit subsidiary of city or county government to administer Healthy Start, and the grantees in Boston and New York were existing nonprofits with strong ties to city government. These arrangements had several advantages. The administrative structures in local government for accounting and data processing did not have to be developed from scratch, and the pre-existing organizational structure could be a source of interim project staff Often those who prepared the grant proposal, these people could begin project activities and hire and supervise the project director, providing a natural, ongoing, and important link with the project throughout its life. In addition, because a nonprofit organization is independent of local personnel and contracting regulations, it had more flexibility to quickly develop its Healthy Start program without a time-consuming approval process.

In contrast to projects with nonprofit status, projects located directly in health departments regretted their lack of flexibility. On the other hand, a primary role for the health department was important to the sustaining Healthy Start beyond the federal grant funding period. Through the influence of health department employees who maintained contact with or were employed by Healthy Start, program features were more likely to become an integral part of future health department activities, either as fully funded free-standing activities or as parts of existing programs.

2. **Selecting and retaining strong senior staff throughout the life of the project was key to successful implementation.**

Leading a Healthy Start project, with an annual multi-million dollar budget, proved to be an extremely challenging job, requiring strong administrative ability (including skills in personnel, accounting, and data systems), experience in community relations, political acumen, and a knowledge of programs related to infant mortality. While it was also ideal to have continuity of

senior staff throughout the life of the project, skilled staff who were recruited later were also very valuable. In addition, it proved to be very advantageous to select staff who were familiar with the Healthy Start community and of the same ethnic group of the majority of community residents.

While it may have been impossible to identify one individual with all of these characteristics, some projects put together a team that had all or most of them. It is not surprising that leadership was important to success; this would be true of any large endeavor. However, the complex nature of leadership in Healthy Start should be recognized, shedding light on the need to hire people appropriate to the job in future demonstrations of similar scope.

3. **It was essential to establish clear and consistent performance standards for contractors, and to closely monitor their compliance with these standards.**

Monitoring was important to the credibility of a program that paid a large amount of public funds to contractors not under the direct oversight of the federal government. Most projects had not developed a thorough approach to monitoring early in the demonstration, although all recognized the need for it. Consequently, the monitoring was uneven across time periods and projects, as well as within projects. In implementing monitoring protocols, projects discovered a persistent internal tension about how strictly to monitor their operations. This was especially true of projects that used a large number of small community-based providers. It was helpful when a "quality improvement" approach was used, including regular meetings to discuss deficiencies and help make improvements so that monitoring was not viewed as an entirely punitive function. Financial monitoring was easier to implement than program monitoring. Developing fair and clear criteria for program success was difficult, and applying those criteria required frequent on-site visits by staff who often had other programmatic responsibilities. Financial and programmatic monitoring were generally handled by different staff, but some projects were able to combine the jobs through the use of special monitoring

staff, who were able to more regularly visit subcontractors and look across all aspects of their program.

4. **A management information system should be clearly defined early in the demonstration, paying special attention to the scope of the data set.**

As discussed in Chapter V, the projects worked hard to collect evaluation data through their MDS systems, but as of this writing, no project had succeeded in collecting a complete data set for any period. However, projects did collect and report some data, demonstrating that, with proper technical assistance, community-based projects such as Healthy Start can collect client-level data. The demonstration showed that the data set should be small (much smaller than the MDS) and that clearer instructions and data definitions should be provided to projects early in the demonstration period. In retrospect, it would have been better for HRSA to have been more descriptive about the methods for gathering and processing data (including provisions of software to grantees); technical assistance should also have been provided earlier in the demonstration period.

C. COMMUNITY INVOLVEMENT

Healthy Start was unique in its strong emphasis on community involvement in the original and ongoing federal guidance for the program. All projects took this mandate seriously, but all found it difficult and challenging. Indeed, all observed that involving the community in the program slowed implementation, a concern given the relatively short demonstration period and the goal of **substantially reducing infant mortality in that short period. Another concern is that community involvement efforts were not always closely linked with infant mortality reduction.**

1. **The role of the consortium in a project's community development strategy should be articulated early in the demonstration.**

Only one community involvement strategy was mandated by HRSA: the community consortium. However, this mandate was interpreted very differently from project to project. Some projects, such as Baltimore, did not view the consortium as an important source of community input or governance. Others, such as Pee Dee, treated the central consortium and local consortia as major components of the intervention. Projects with very active consortia devoted a great deal of energy and time to convening and sustaining the consortia. At times, the community consortium mandate was interpreted very differently by those involved, leading in these circumstances to substantial staff and community frustration. Conflict detrimental to project progress arose in a small number of projects when community members learned that "community-based decision making" did not, for example, mean that the consortium had the power to control the project budget. (When such conflict was severe, outside consultants proved to be effective in improving consortium/staff relationships.) To avoid some of the discord and related implementation delays experienced by some Healthy Start projects and communities, future community-based demonstration projects requiring a consortium need to define clearly the purpose and roles of that organization before the demonstration begins.

2. **Consumer involvement in the central consortia was weak across all projects despite a variety of strategies to involve consumers. Organizing local consortia was a potentially more useful approach for increasing consumer involvement.**

All projects wanted consumers to be involved in their consortia. Also, HRSA emphasized the importance of this in its guidance and technical assistance. While projects adopted a variety of strategies to involve consumers--such as transportation assistance, child care, and adjusting the place and time of meetings-their involvement remained weak even though it grew somewhat late in the demonstration period. Many central consortia primarily included as active members the groups and

individuals that prepared the original grant proposal, several of whom were state and local officials or provider representatives. Projects reported that consumers felt intimidated by the professional composition of consortia and by formal consortium structures and committees. Projects also reported that consumers were often personally not strongly concerned about infant mortality.

The most promising strategies to emerge to address this weakness were training and smaller, less formal committees that met in the community. But even in these "local consortia," community-based providers receiving Healthy Start funds were often more active than consumers. And the effort and time required to organize these groups was a strain on program staff. Still, site visitors judged local consortia to be the most promising avenue for consumer and other forms of "grass roots" community involvement in Healthy Start. The local evaluation in Cleveland is focusing' on consortia efforts there, and the evaluation findings should help inform future efforts in the area.

The ability to organize local consortia depends on having staff specially trained in community organizing. However, organizations that do this kind of work--such as community development agencies or other neighborhood-based nonprofits--may not have the same philosophical or service orientation as the Healthy Start program. Although this approach (i.e., using outside consultants or organizations) may alleviate the strain on program staff, it should not be the only approach.

3. **Provider involvement in the consortia was very useful for developing service networks but also had the potential to lead to conflicts of interest in subcontracting.**

While projects did not establish formal, closed provider networks, they used various mechanisms to provide a forum in which many different providers could interact, thus increasing the exchange of information and facilitating appropriate referrals. This was accomplished primarily through consortium and committee activities.

As mentioned, providers were often influential in developing the original Healthy Start proposal and may have already had a defined role in service delivery as part of that process. Other providers may have "come to the table" hoping for a new or expanded role in the project. This financial incentive was only one reason for involvement (others included commitment to the health issues involved and to improving systems of care), and overall provider involvement was very beneficial to the project.

Over time, almost all projects realized the need to have guidelines for conflicts of interest, although these guidelines were applied with varying degrees of strictness. One common strategy was to preclude provider consortium members from participating in budget deliberations or any decisions about selecting service provider subcontractors. If Healthy Start expands or if other similar demonstrations with consortia are implemented, Healthy Start experience should be used to provide guidance about the best way to include providers in a consortium.

4. **Employment strategies, including hiring local residents and contracting with small businesses in the community, broadened community involvement and interest in the project.**

Projects found that infant mortality was not a very important issue for most community residents, but that economic issues stimulated community interest and involvement. Employing residents of Healthy Start communities to deliver some form of services (usually outreach/case management services) was a common strategy to increase community involvement in all Healthy Start projects. Some projects have played a critical role in job training and job creation in their communities. This was true for Baltimore, where the target area was small and the number of community residents employed was large. Very heavy employment of community residents also holds risks, since a large number of employees might not be able to find other jobs if reduced federal funding for Healthy Start causes cutbacks.

An alternative to employing residents directly as a means of involving the community was to contract with community-based providers for services, since such organizations were themselves likely to employ community residents. Selecting providers was often fully or partly delegated to local consortia, giving these groups a substantial and useful role. To the extent that communities developed businesses that would continue beyond grant funding, this strategy was potentially more sustainable than direct employment of community residents. (For example, the development of Medicaid managed care provides the opportunity for such businesses to contract with managed care organizations for outreach, transportation, and other support services in Healthy Start communities.)

However, projects found that reliance on "grass roots" providers required substantial technical support from the grantee. For example, technical assistance was often needed to prepare responses to solicitations for proposals or budget revisions. Also, community-based organizations often needed help in developing an administrative structure for payroll, accounting, and demonstration reporting. In addition, the time required by project staff to solicit and review proposals, award contracts, and monitor performance was great, since the use of grass roots providers usually resulted in a large number of small contracts spread across many providers.

D. SERVICE DELIVERY

The demonstration revealed several important lessons about developing new services and enhancing the service delivery systems in different communities.

1. Models of service delivery and their relationship to reducing infant mortality should be clearly defined before services are delivered. Community involvement complicates this process.

Many projects began delivering services (or contracting for those services) before they had clearly articulated why they wanted to deliver the service, what they wanted to accomplish by

delivering the service, and how the service related to infant mortality. This made it more difficult to establish interim objectives that could be used to measure progress. In many ways, this is a challenge inherent in implementing a truly community-based project. The community is generally more concerned with the services it perceives to be necessary than with establishing measurable objectives for the program. As a result, evaluators risk losing a community's trust in a project with the introduction of project "research" or "evaluation" issues. Educating the community about the importance of measurable objectives is therefore a critical early step. This also facilitates the development of service delivery protocols, which, in turn, make it easier to monitor contractors and consistency of service delivery across multiple sites.

2. **Healthy Start projects filled important gaps in services, reaching beyond the traditional scope of clinical care.**

The services provided by Healthy Start, either directly or through contract, were often not provided in traditional clinic settings. These included outreach, case management, and support services such as transportation and nutrition education. These support services are generally not provided in traditional clinic settings, despite their value in filling gaps in the service delivery system and creating a more seamless and user-friendly system of care for higher risk women and children. As managed care becomes a more dominant component of health care systems, these facilitating and coordinating services may receive greater attention. **HRSA** and other organizations can learn a great deal about how to deliver such services and what they cost from the Healthy Start experience.

3. **Outreach and case management by lay workers is a promising approach to reaching high-risk women and bringing them into care.**

Outreach and case management, the central service components implemented by all Healthy Start projects, were intended to identify, reach, and bring high-risk women into the health care

delivery system. Given the variation in how O/CM was defined and in the intensity with which services were implemented, the picture of O/CM in Healthy Start reveals a wide range of personnel types, caseloads, and activities.

Classifying models of case management and implementing a variety of such systems using more standardized models may be possible in the new Healthy Start projects. This would allow HRSA to more carefully explore the effectiveness of particular models. The lay worker model, which was implemented in most projects, holds great promise for providing services that are accessible and satisfying to mothers served by Healthy Start. This model appears to work best when it (1) is implemented by teams with relatively low ratios of lay workers to professional workers, (2) incorporates intensive and ongoing training and mentoring, and (3) keeps caseloads relatively low--especially for the lay workers.

4. **It is efficient to devote resources to modifying and expanding services in existing clinical service delivery sites.**

Healthy Start projects evolved within an existing service delivery environment. Particularly in the urban settings, projects believed that modifying and coordinating existing services was more important than creating new services. Many projects used funds specifically to improve the existing service delivery system rather than to develop new services. Modifications included adding child care or play areas, adding critically needed staff, improving appointment tracking, and expanding hours.

5. Coordination of care was a major focus of all Healthy Start projects.

While projects did not establish formal, closed provider networks, they used various mechanisms to provide a forum in which many different providers could interact, increasing the

exchange of information and facilitating appropriate referrals. The primary mechanisms included consortium and committee activities and the O/CM process.

6. **Many Healthy Start service interventions were not closely tied to infant mortality.**

Since Healthy Start projects, for the most part, implemented a nontraditional service model, the link between Healthy Start services and infant mortality was often unclear and untested. Consequently, Healthy Start should be considered a long-term, rather than a short-term, strategy for reducing infant mortality. It is possible that the impact of the demonstration on infant mortality will not be observed in the relatively short period of the national evaluation.

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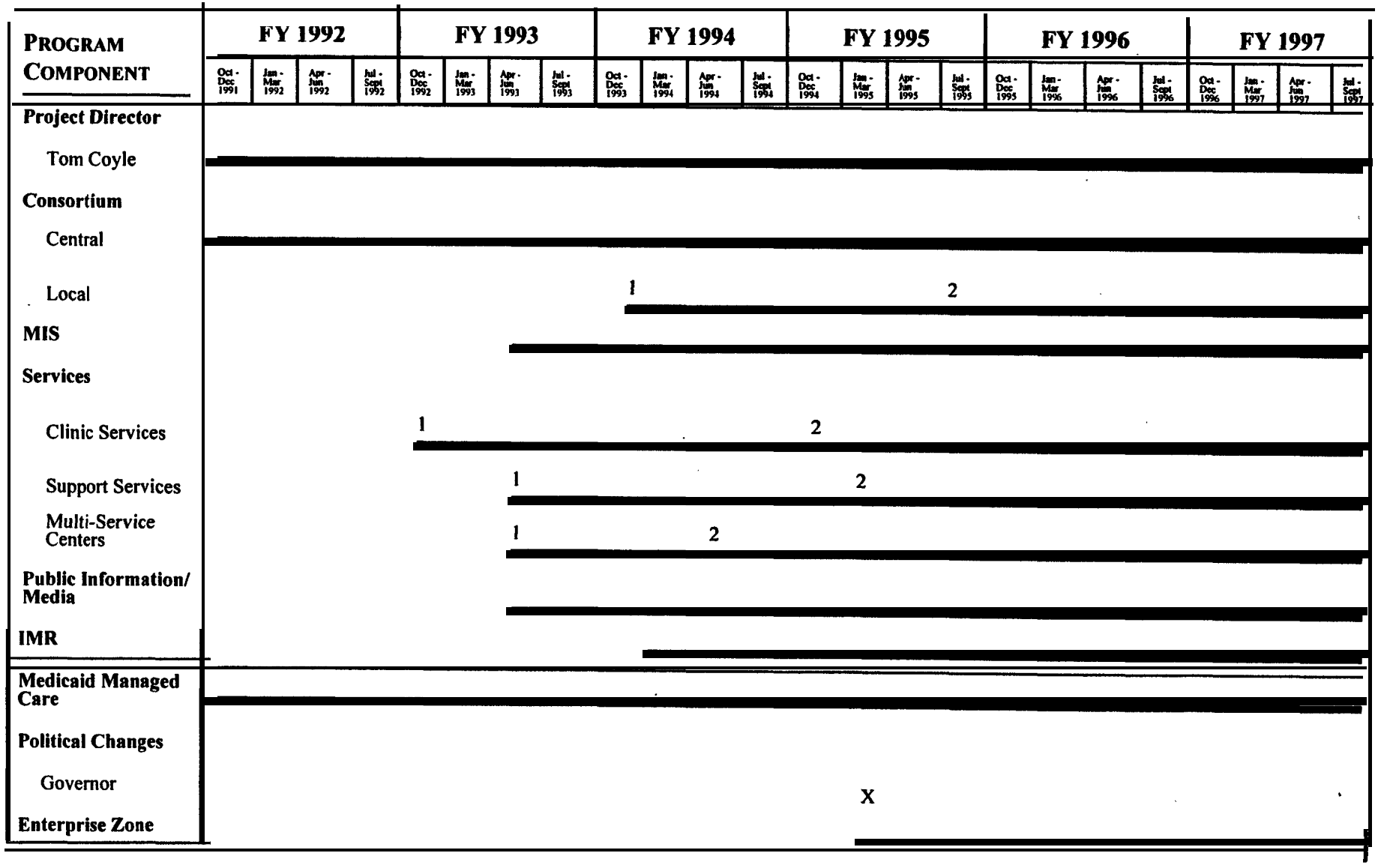
APPENDIX A

TIME LINES FOR HEALTHY START IMPLEMENTATION

FIGURE A.

BALTIMORE HEALTHY START TIMELINE



BALTIMORE HEALTHY START
TIMELINE NOTES

Local Consortium

1. West
2. **East**

Clinic Services

1. Medical Reform
2. Special Hospital Services

Support Services

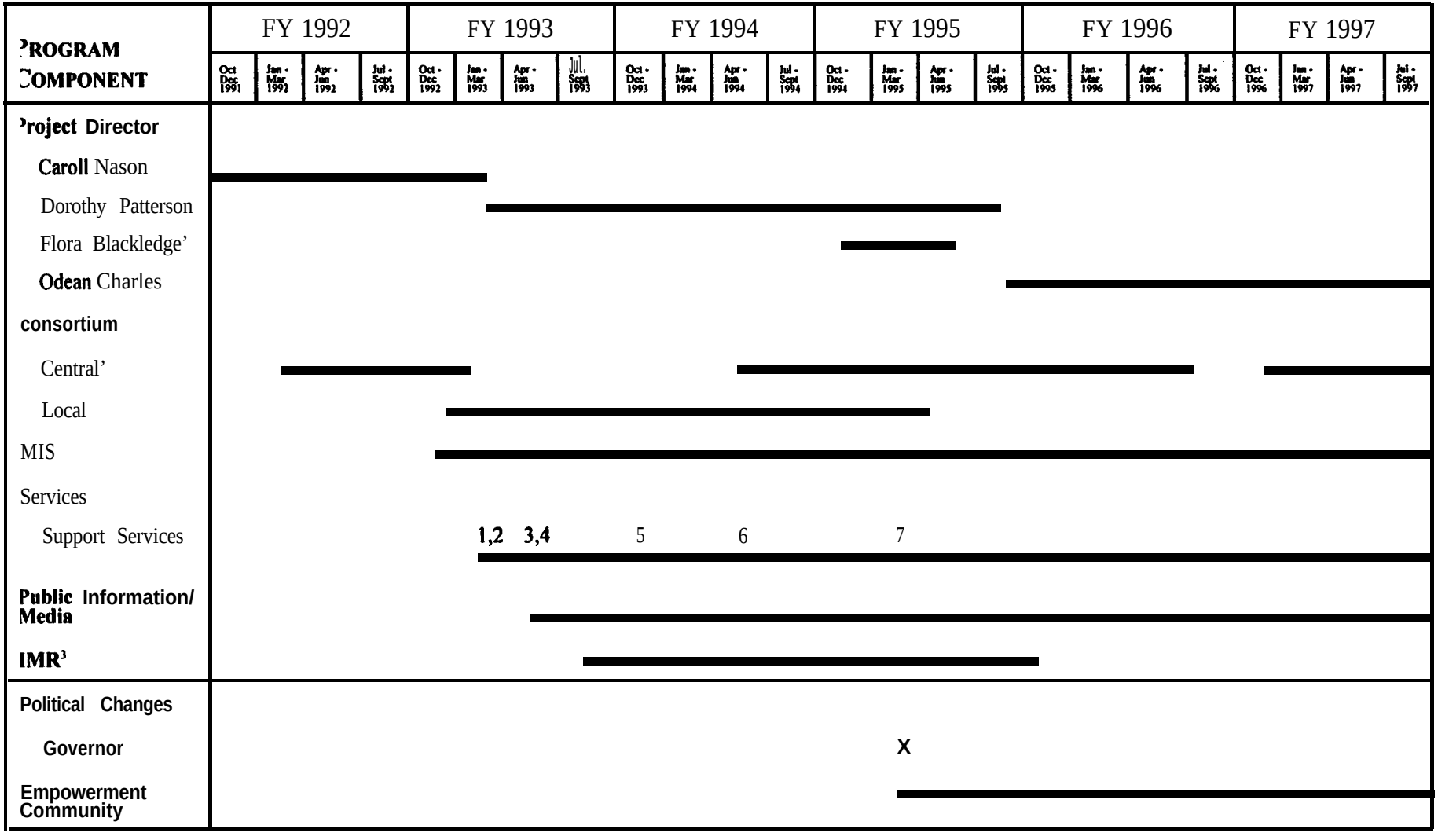
1. **Men's** Services
2. Maternal and Infant Nursing Program

Multi-Service Centers

1. Neighborhood Healthy Start Center West
2. Neighborhood Healthy Start Center East

FIGURE A.2

BIRMINGHAM HEALTHY START TIMELINE



[1]F. Blackledge was co-director over service delivery from 10/94 - 4/95.
[2]Central and local consortia were merged in 1995 and disbanded in 9/96. A client/consumer advisory panel was formed in 12/96.
[3]The IMR continues under JCDH, the grantee.

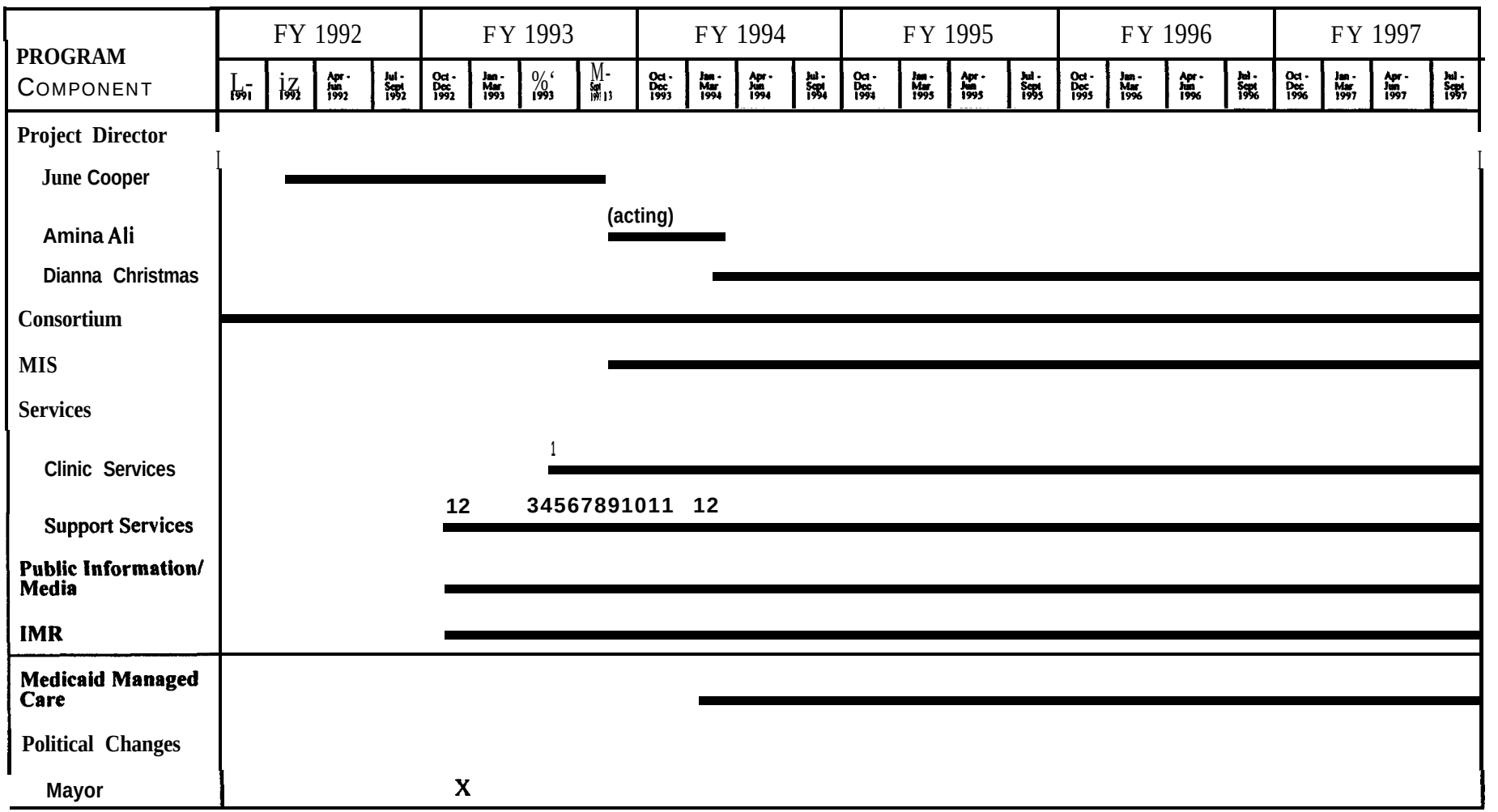
BIRMINGHAM HEALTHY START
TIMELINE NOTES

Support Services

1. Case Management (1/93 - 10/95)
2. Outreach
3. Health Education
4. Nursing (6/93 - 9/95)
5. Helpline
6. Contracted Services
7. Health Diaries (3/95 - 9/95)

FIGURE A.3

BOSTON HEALTHY START INITIATIVE **TIMELINE**



BOSTON HEALTHY START INITIATIVE
TIMELINE NOTES

Clinic Services

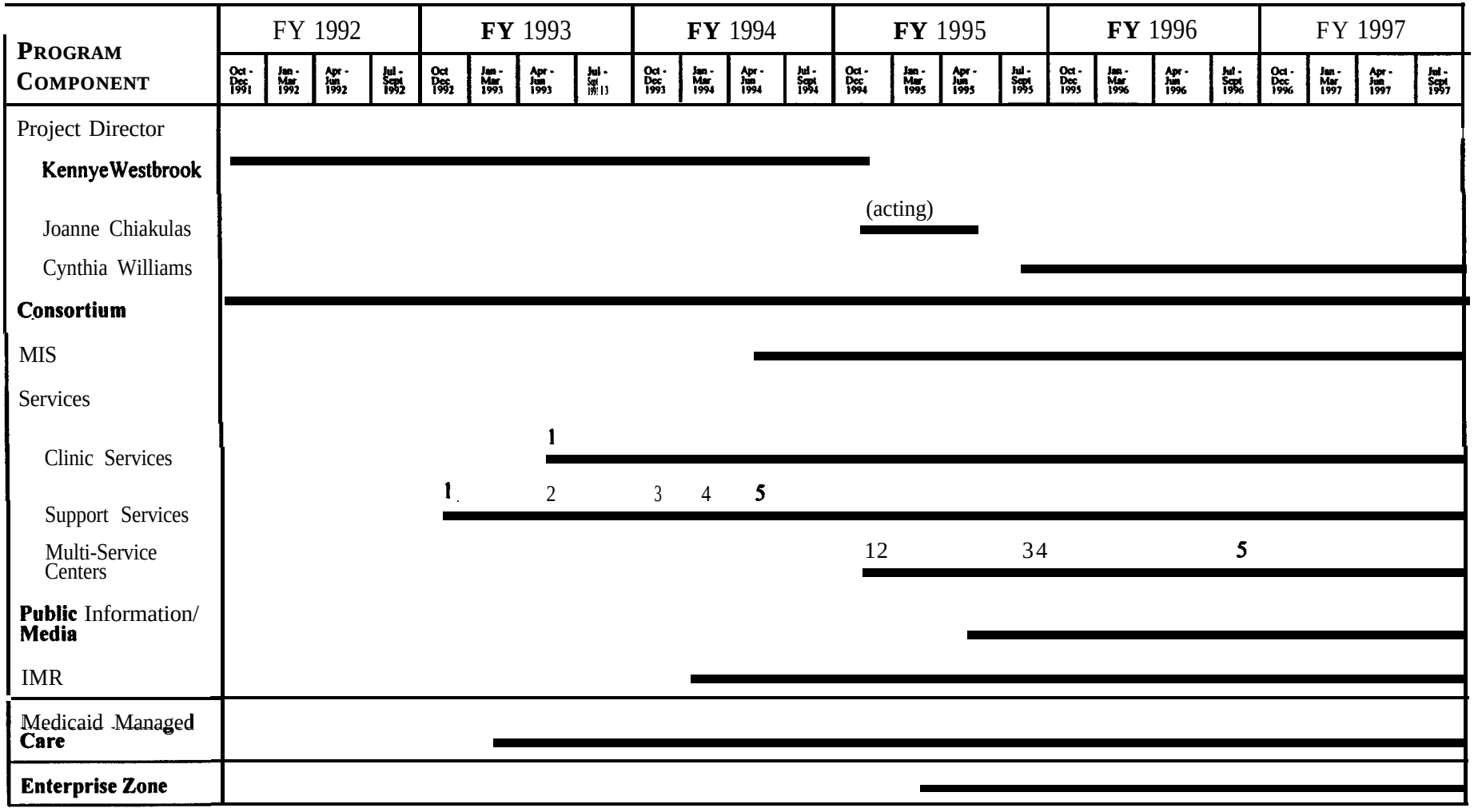
1. Health Center Capacity/Enhancements

Support Services

1. Case Management
2. School-based Services
3. Domestic Violence Services
4. Perinatal Substance Abuse Services
5. Nutrition Services
6. Smoking Cessation
7. Infant Health Care
8. Women's Health Education
9. Youth Outreach
10. Teen Leadership
11. Adult Education
12. Outreach to Non-clinical Sites

FIGURE A.4

CHICAGO HEALTHY START TIMELINE



CHICAGO HEALTHY START
TIMELINE NOTES

Clinic Services

1. Primary Care Expansion

Support Services

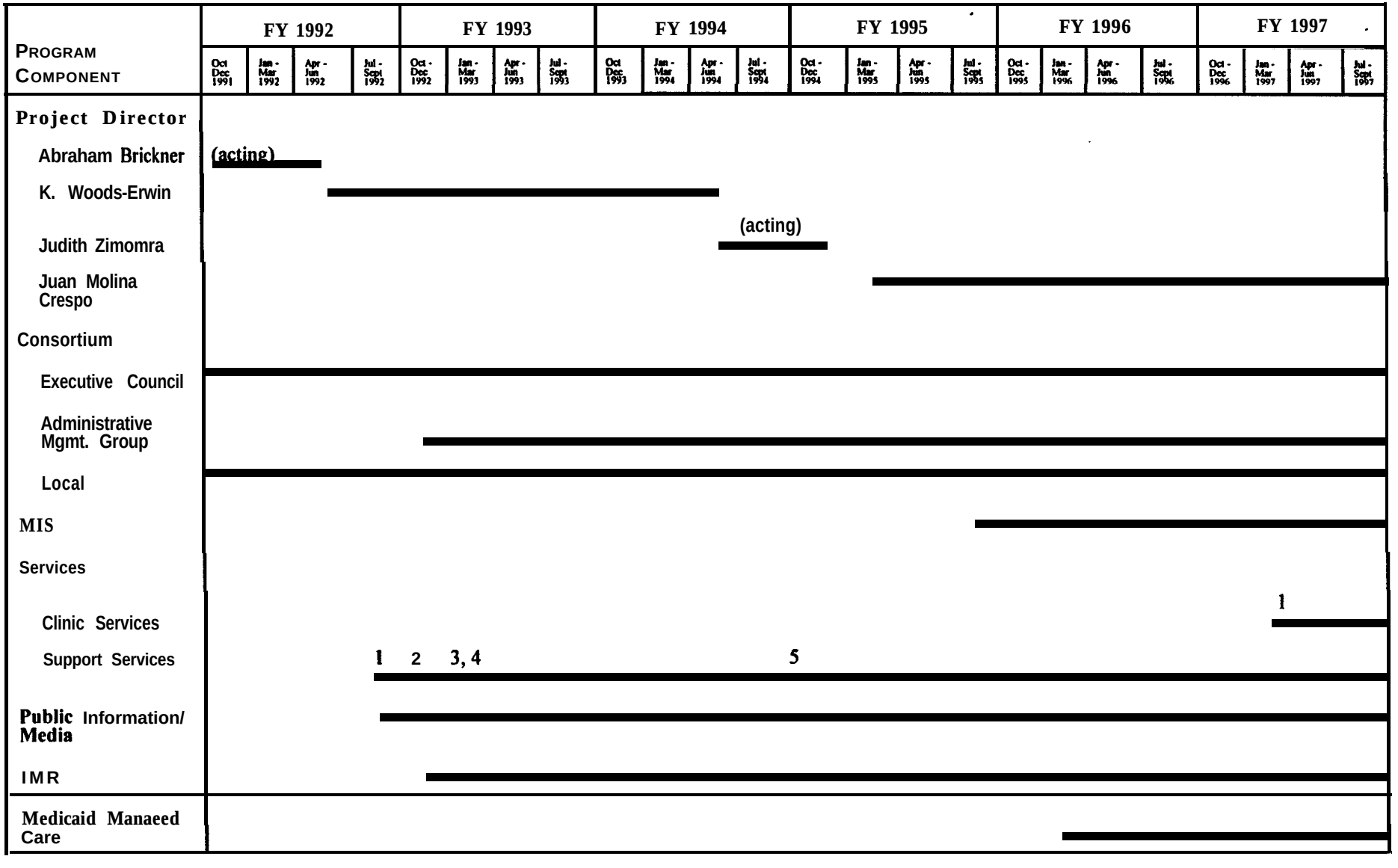
1. Case Management
2. Jail Services
3. O-3 Intervention
4. Substance Abuse Services
5. Healthy Families Violence Prevention

Multi-Service Centers

1. **HIMRI** Family Service Center **(FSC)**
2. Henry Booth House FSC
3. West Side Future FSC
4. **Winifield** Moody FSC
5. Chicago Urban League FSC

FIGURE A.5

. GREATER CLEVELAND HEALTHY FAMILY/
HEALTHY START PROJECT TIME LINE



CLEVELAND HEALTHY FAMILY/HEALTHY START
TIMELINE NOTES

Clinic Services

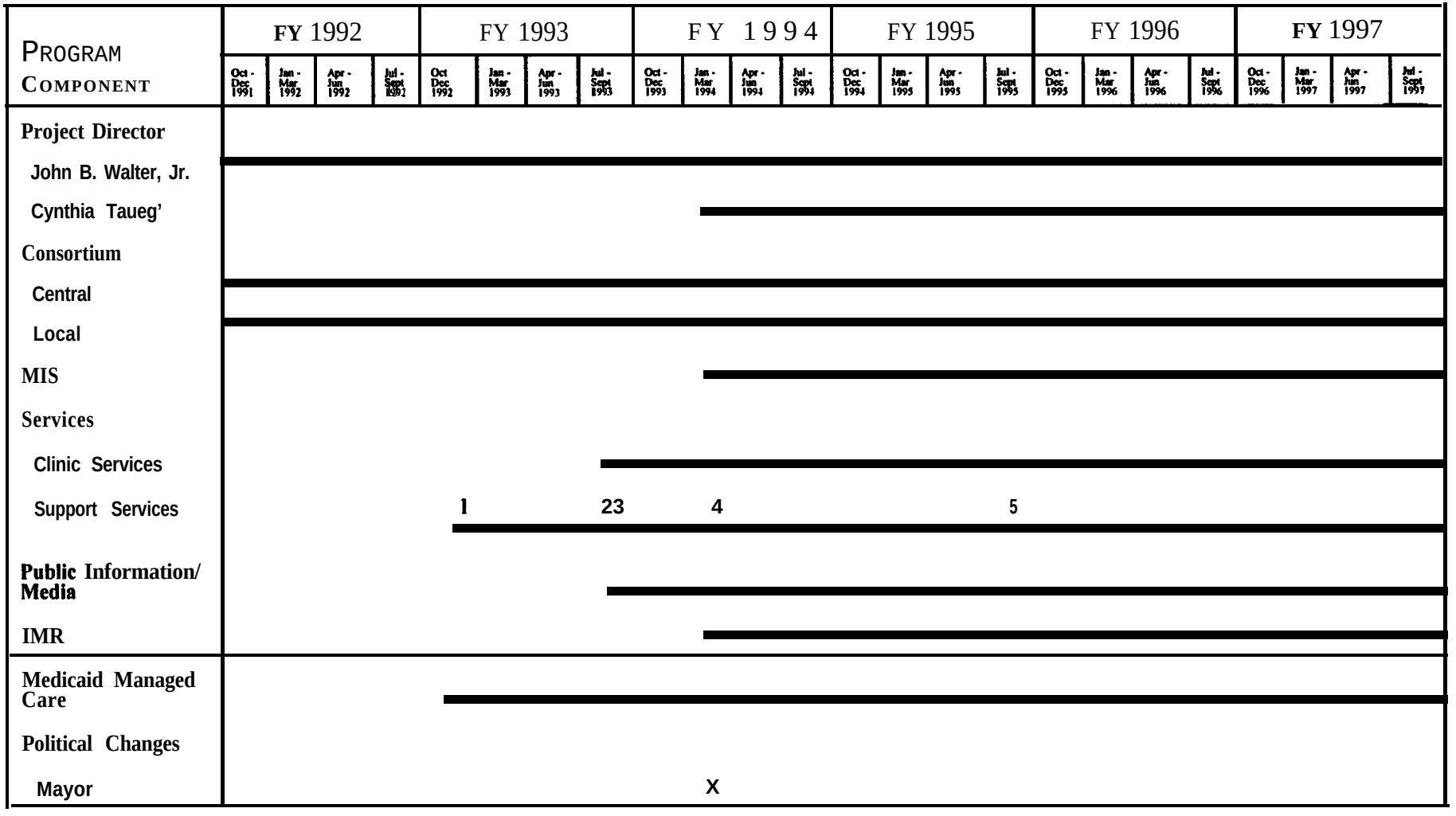
1. MOMobile

Support Services

1. Outreach
2. Male Services (10/92 - 9/96)
3. Substance Abuse Treatment
4. NCA
5. School Outreach

FIGURE A.6

DETROIT HEALTHY START TIMELINE



NOTE: 'Cynthia Taueg became co-project director shortly after assuming the position of director of the Detroit Health Department. Dates and information still under review.

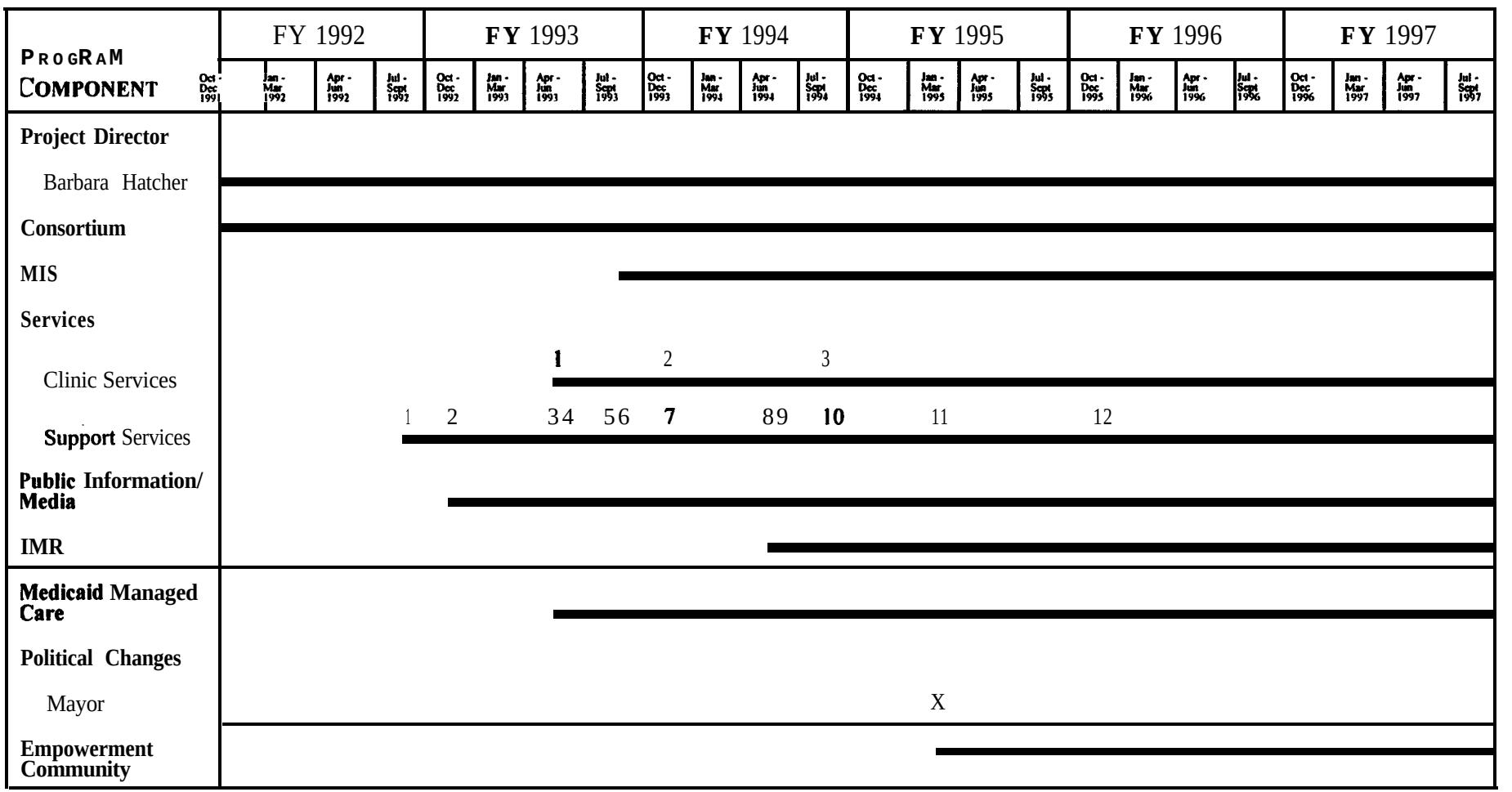
DETROIT HEALTHY START
TIMELINE NOTES

Support Services

1. Case Management
2. Public Health Support Services (9/93 - 9/96)
3. Transportation
4. Community Development Initiatives
5. Male Partner Services

FIGURE A.7

DC HEALTHY START TIMELINE



DC HEALTHY START
TIMELINE NOTES

Clinic Services

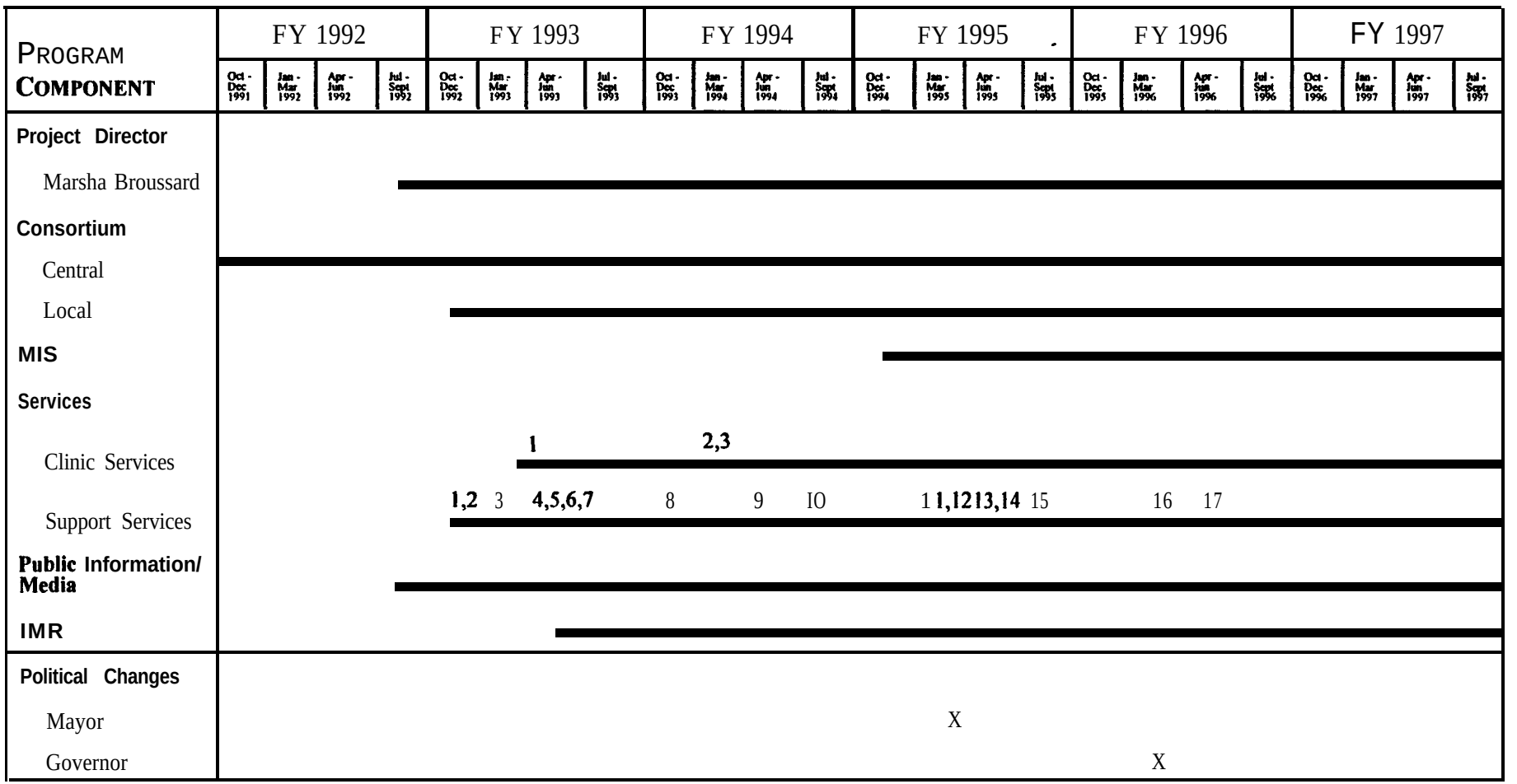
1. Health Clinic Service Enhancements
2. Mom Mobile
3. School Clinic

Support Services

1. Health Education
2. Outreach
3. Substance Abuse
4. Family Planning
5. Transportation
6. Case Management
7. Nutrition Services
8. Mental Health Services
9. Sister Friends
10. Male Involvement
11. Peer Educators
12. Resource Center

FIGURE A.8

NEW ORLEANS GREAT EXPECTATIONS **TIMELINE**



NEW ORLEANS GREAT EXPECTATIONS
TIMELINE NOTES

Clinic Services

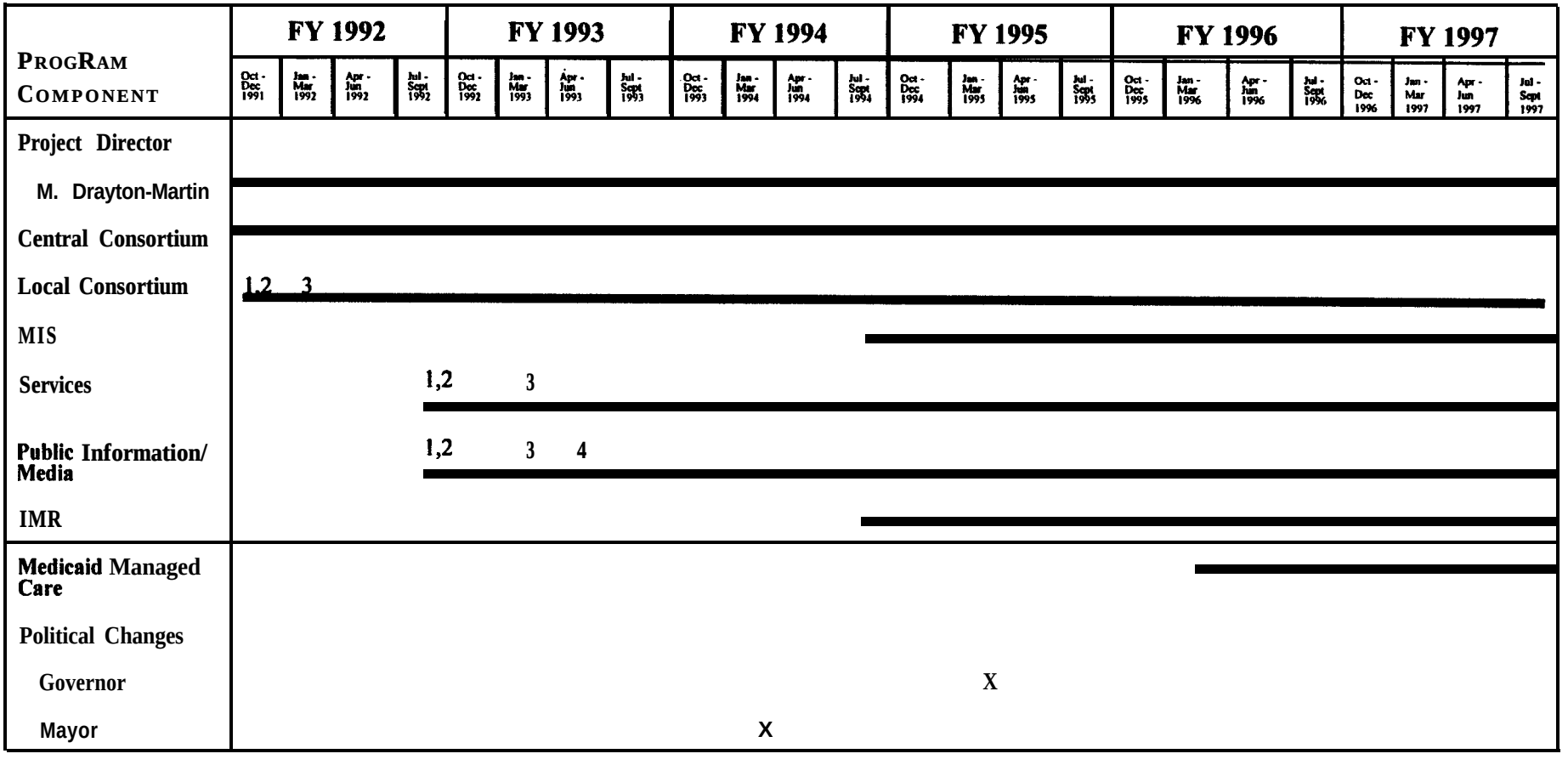
1. Enhanced Clinical
2. School-based Clinical (1/94 - 9/96)
3. Community Health Nursing

Support Services

1. Low Risk Case Management
2. Transportation
3. High Risk Case Management
4. Male Involvement
5. Parenting Education
6. Outreach
7. Substance Abuse Treatment
8. Teen Awareness
9. Hispanic Services
10. Prenatal Education
11. Grief Counseling
12. Substance Abuse Outreach
13. Smoking Cessation
14. Peer Counseling
15. Family Planning Initiative
16. Theater Program (6/96 - 9/96)
17. Consumer Development

FIGURE A.9

HEALTHY START/NEW YORK CITY TIMELINE



HEALTHY START/NEW YORK CITY TIMELINE NOTES

Local Consortium

1. Mott Haven
2. Bedford
3. Central Harlem

Services

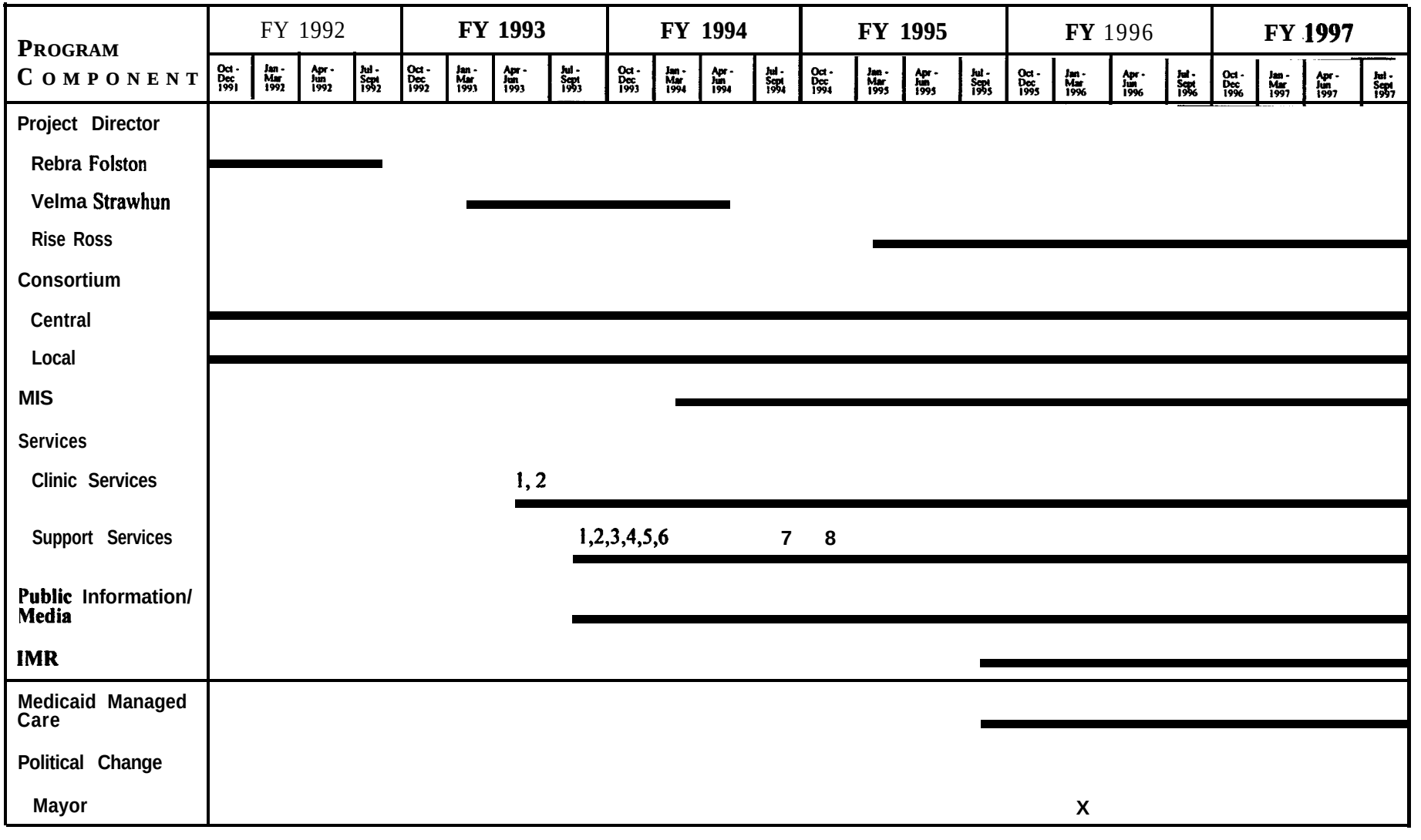
1. Mott Haven
2. Bedford
3. Central Harlem

Public Information/Media

1. Mott Haven
2. Bedford
3. Project Area
4. Central Harlem

FIGURE A.10

NORTHWEST INDIANA HEALTHY START TIMELINE



NORTHWEST INDIANA HEALTHY START
TIMELINE NOTES

Clinic Services

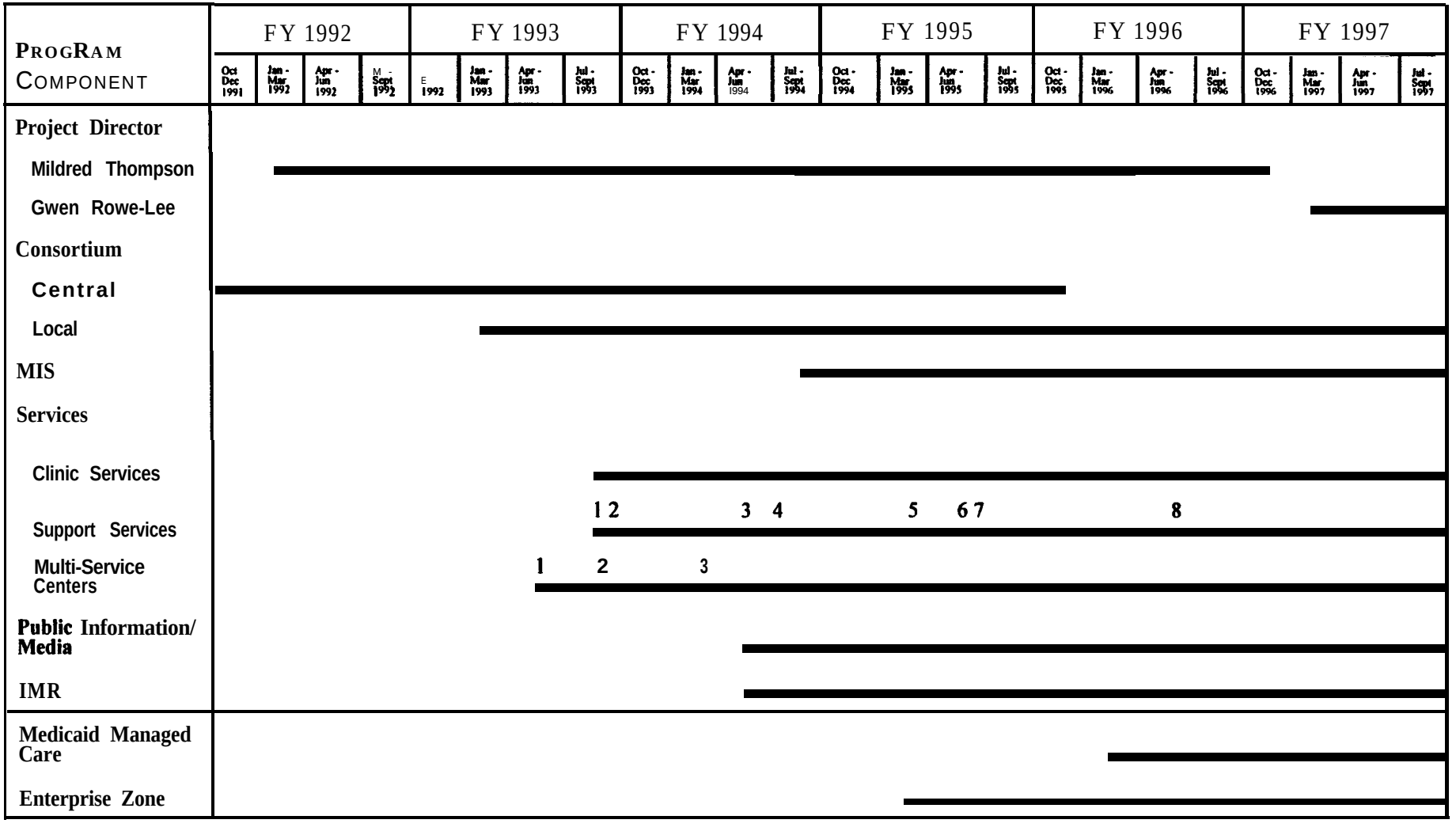
1. Hospitals/FSCs
2. School Nurses (5/93 - 9/96)

Support Services

1. Transportation
2. Parent Education/Resource Center
3. Case Management
4. Smoking Cessation
5. Child Care
6. Parenting Education
7. Alternative School
8. Healthy Families

FIGURE A. 11

OAKLAND HEALTHY START **TIMELINE**



OAKLAND **HEALTHY** START
TIMELINE NOTES

Support Services

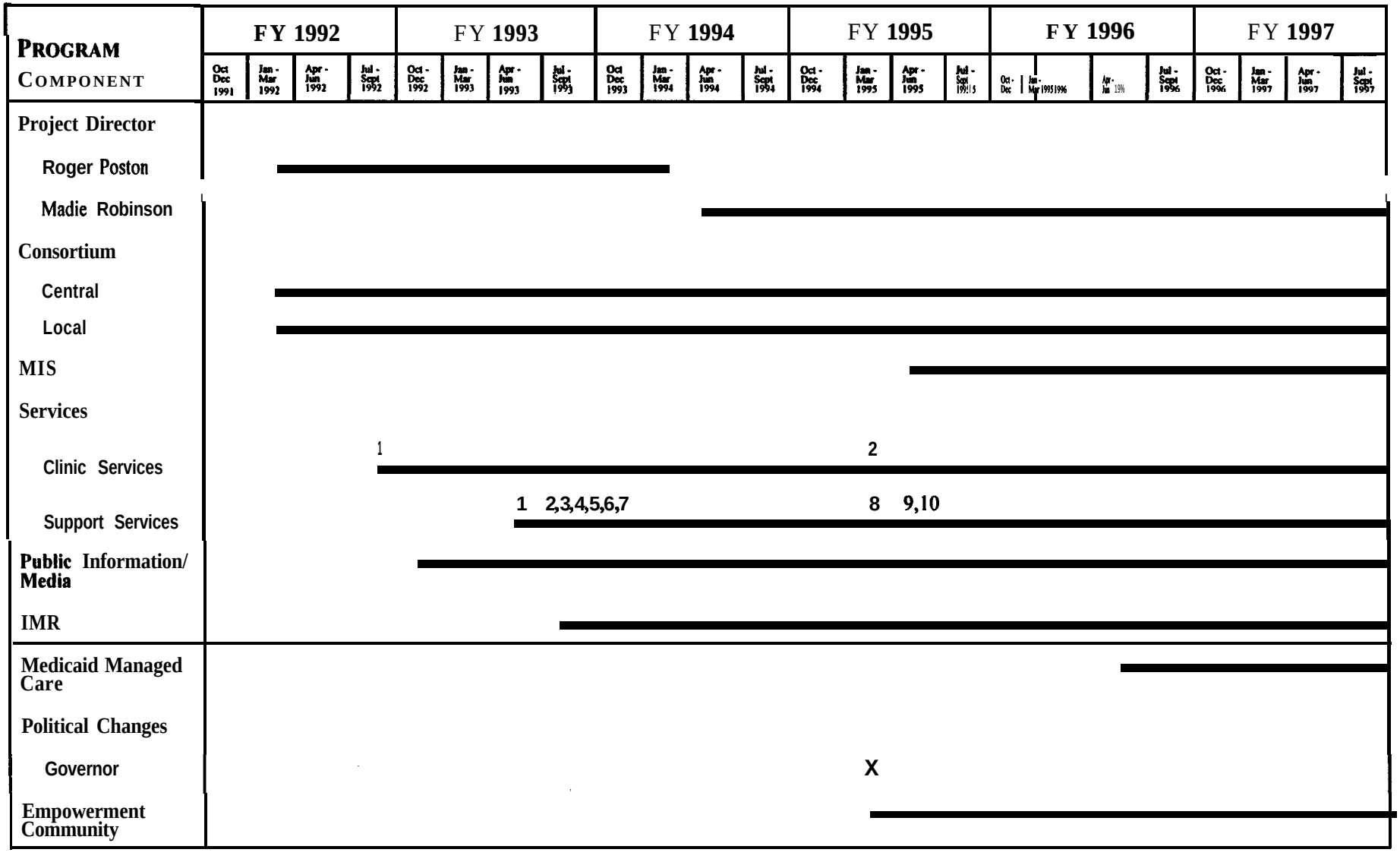
1. High-risk **Infant** Follow-up
2. Family Support
3. Cultural Competency
4. Prison Services **(8/94 - 8/95)**
5. Teen Programs
6. Transportation
7. Domestic Violence Services
8. Substance Abuse

Multi-Service Centers

1. West Oakland **(5/93 - 8/94 3/95 -** present)
2. Ujima House
3. **Asha** House

FIGURE A.12

PEE DEE HEALTHY START TIMELINE



PEE DEE HEALTHY START
TIMELINE NOTES

Clinic Services

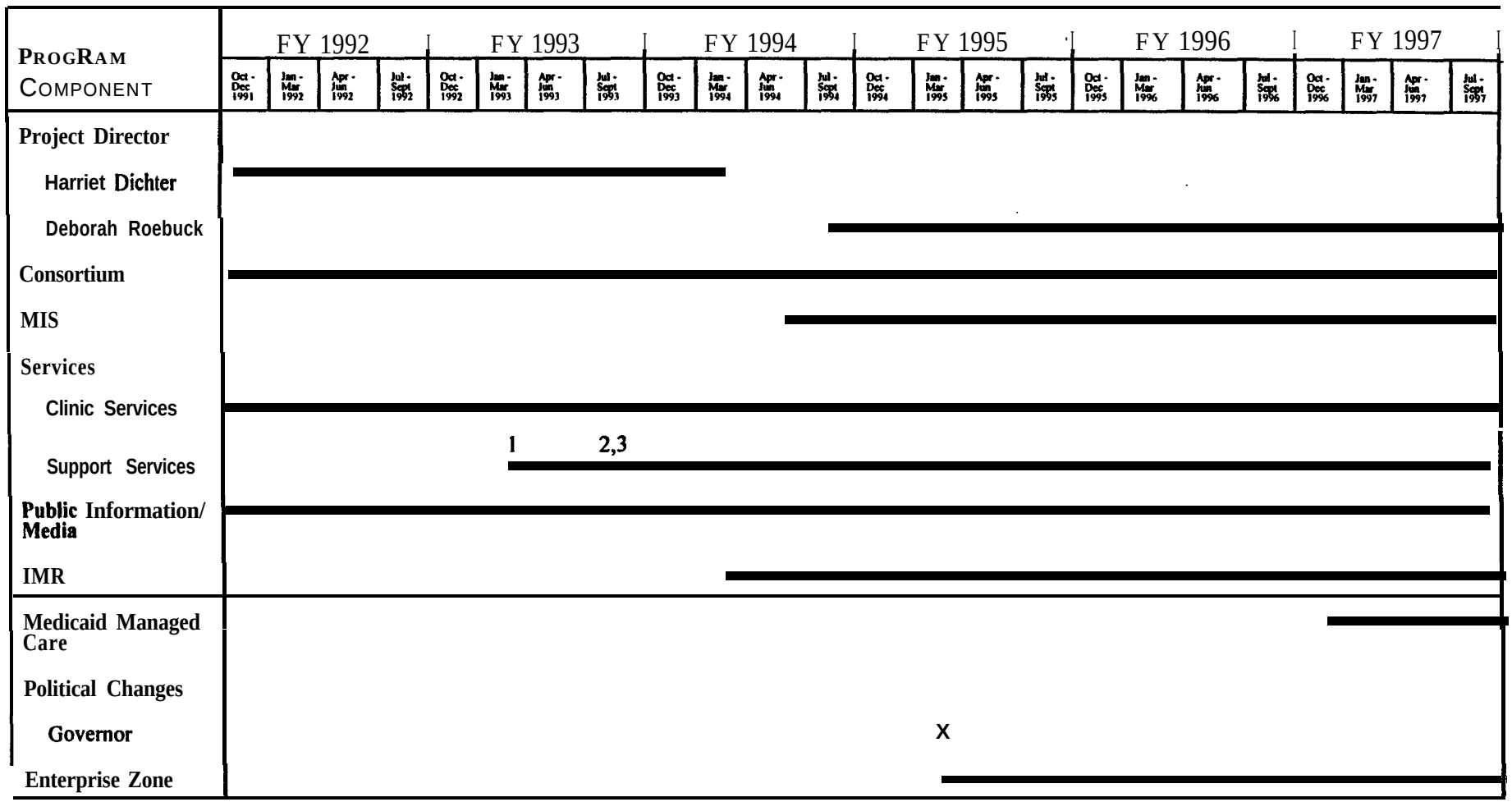
1. Provider Recruitment
2. School Health

Support Services

1. Economic Development
2. ROADS **Teams**
3. Teen Life Centers
4. AOD Counselors
5. Outreach Parenting
6. Interfaith Initiatives
7. Child Care
8. Nurturing Centers
9. Family Intervention
10. Transportation

FIGURE A.13

PHILADELPHIA HEALTHY START **TIMELINE**



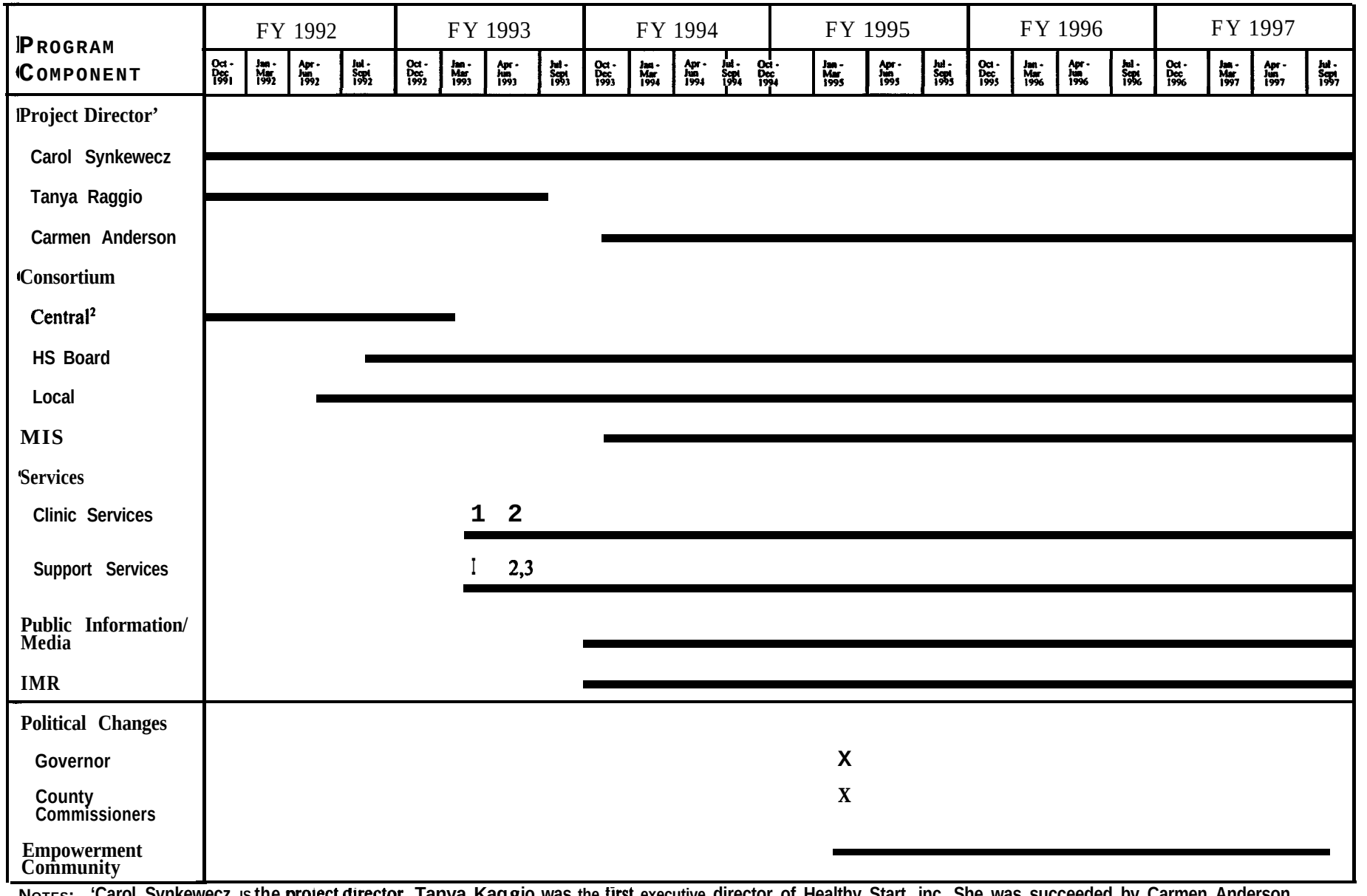
PHILADELPHIA HEALTHY START
TIMELINE NOTES

Support Services

1. Community Education
2. Lay Home Visiting
3. Outreach

FIGURE A.14

PITTSBURGH HEALTHY START TIMELINE



NOTES: 'Carol Synkewecz is the project director. Tanya Kaggio was the first executive director of Healthy Start, inc. She was succeeded by Carmen Anderson.
[2]The central consortium discontinued meeting regularly in early 1993. It now meets for selected task committees and advice and support.

PITTSBURGH HEALTHY START
TIMELINE NOTES

Clinic Services

1. Specialty Contracts
2. Family Planning

Support Services

1. Core Teams
2. Specialty Contracts
3. Male Services

APPENDIX B

MAP OF HEALTHY START SERVICE AREAS

TABLE B. 1

DEFINITIONS OF HEALTHY START SERVICE AREAS

Site	Definition of Project Area
Baltimore[a]	Census Tract: 603.00, 604.00, 605.00, 702.00, 703 .OO, 704.00, 803.01, 804.00, 807.00, 808.00, 1001.00, 1002.00, 1402.00, 1403.00, 1501.00, 1502.00, 1601.00, 1602.00, 1603.00, 1604.00
Birmingham	Census Tract: 30.01, 31.00, 36.00, 37.00, 38.02, 4.00, 5.00, 24.00, 22.00, 19.02, 1.00, 23.03, 32.00, 33.00, 34.00, 35.00, 7.00, 8.00, 55.00, 15.00, 16.00, 27.00, 11.00, 12.00, 14.00, 29.00, 30.02, 57.01, 57.02, 130.02, 131.00, 42.00, 51.01, 51.02, 38.03, 39.00, 40.00, 52.00, 3.00, 23.04, 23.05
Boston	Census Tract: 7.01-7.12, 8.01-8.21, 9.01-9.24, 10.01-10.05, 10.09-10.1 1, 11.01, 12.02, 12.03, 12.05-12.07, 14.01, 14.03, 14.04
Chicago	Census Tract: 8.03-8.09, 8.18, 8.19, 2401.00-2436.00, 2801.00-2843.00, 3301.00-3305.00, 3501.00-3515.00, 3801.00-3820.00
Cleveland	Census Tract: 10.54-10.56, 11.94, 11.95, 11.97, 10.79, 10.87, 10.88, 10.89, 10.93, 10.96, 10.97, 10.98, 10.99, 11.03, 11.37, 11.38, 11.42, 11.29, 12.11, 12.12, 12.14-12.16, 11.79, 12.61, 11.63, 11.66-11.68, 11.84, 11.14, 11.61, 11.62, 11.64, 11.65, 11.81, 11.82, 11.83, 11.85, 10.75, 10.81-10.86, 11.11, 11.43-11.45, 11.47, 11.48, 12.01, 12.17-12.19, 12.21-12.23, 11.98, 11.99, 12.06-12.08, 11.12, 11.13, 11.15-11.19, 11.55, 11.56, 12.04, 12.05, 12.09, 12.13, 11.93, 11.96, 12.02, 11.21-11.28, 11.86, 11.89, 18.81
Detroit	Census Tract: 5037.00-5047.00, 5052.00, 5053.00, 5 101 .OO, 5 107.00-5117.00, 5121.00-5151.00, 5255.00, 5156.00, 5162.00, 5174.00-5188.00, 5201.00-5206.00, 5223.00, 5224.00, 5301.00-5334.00, 5341.00-5344.00, 5347.00-5352.00, 5356.00-5357.00, 5361.00-5374.00, 5377.00-5378.00, 5424.00-5426.00, 5530.00-5537.00
District of Columbia (D.C.)	Census Tract: 7.63, 7.64, 7.73, 7.77, 7.78, 7.83-7.85, 7.87, 7.88, 9.61-9.64, 9.91-9.97, 7.31, 7.32, 7.34, 7.38, 7.41, 7.44-7.48, 7.52, 9.70, 9.81-9.89

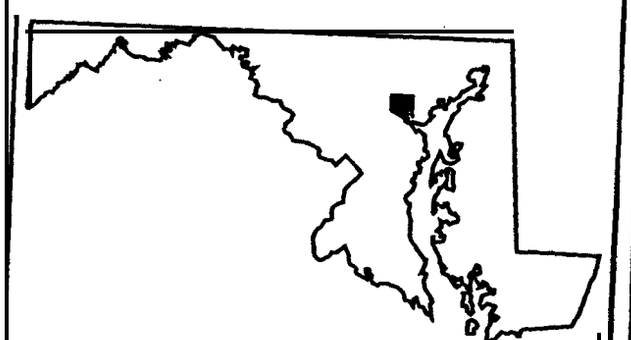
TABLE B. 1 *(continued)*

Site	Definition of Project Area
New Orleans	Census Tract: 7.01, 7.02, 8.00, 9.01-9.04, 11.00, 12.00, 13.01-13.04, 14.01, 14.02, 15.00, 16.00, 17.03, 17.98, 18.00, 19.00, 20.00, 21.00, 22.00, 23.00, 24.01, 24.02, 33.05-33.08, 27.00, 28.00, 29.00, 30.00, 31.00, 34.00, 35.00, 36.00, 37.02, 39.00, 40.00, 44.01, 44.02, 45.00, 48.00, 49.00, 60.00, 63.00, 69.00, 59.00, 67.00, 68.00, 79.00, 80.00, 84.00, 85.00, 86.00, 91.00, 92.00, 93.01, 93.02, 94.00, 100.00, 102.00, 77.00, 78.00, 81.01, 81.02, 82.00
New York	ZIP Code: 11213, 11216, 11221, 11225, 11233, 10026, 10027, 10030, 10037, 10039, 10451, 10454, 10455, 10474
Northwest Indiana	City Code (1988+) in County 45: 21, 23, 31, 46
Oakland	Census Tract: 10.00-19.00, 21.00-25.00, 27.00, 28.00, 30.00, 31.00, 34.00, 49.00, 50.00, 54.00, 55.00, 57.00-63.00, 70.00, 71.00, 74.00-76.00, 84.00-89.00, 91.00, 94.00-97.00, 102.00, 103.00
Pee Dee	County Code: 13, 16, 17, 34, 35, 45
Philadelphia	ZIP Code: 19151, 19131, 19139, 19104, 19143, 19142, 19153
Pittsburgh	Census Tract: 321.01-321.03, 321.06, 322.01-322.05, 323.01-323.03, 324.01-324.03, 325.01-325.03, 325.06, 326.03-326.06, 326.09, 326.10, 301.01, 302.01, 302.02, 303.02, 303.04, 303.05, 304.01, 304.02, 304.07, 304.08, 305.01-305.06, 305.08, 305.09, 306.01, 306.02, 306.05, 556.01, 556.04-556.06, 556.10-556.13, 311.01, 311.02, 311.04, 311.06, 311.09, 311.10, 312.01-312.04, 312.07, 312.08, 313.01-313.08, 310.04-310.08, 314.05, 316.01-316.08, 317.01-317.03, 318.01-318.06, 329.01-329.03, 330.01, 319.01-319.07, 320.12, 546.37-546.39, 328.07, 328.08, 548.67-548.69, 551.36, 551.37

"Baltimore figures define the project's two target areas within the larger project area.

FIGURE 1

BALTIMORE



MARYLAND

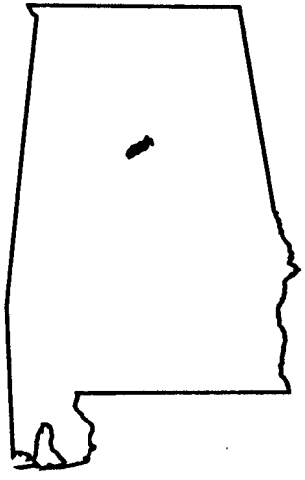
Participation in Healthy Start by Census Tract

Demonstration Area

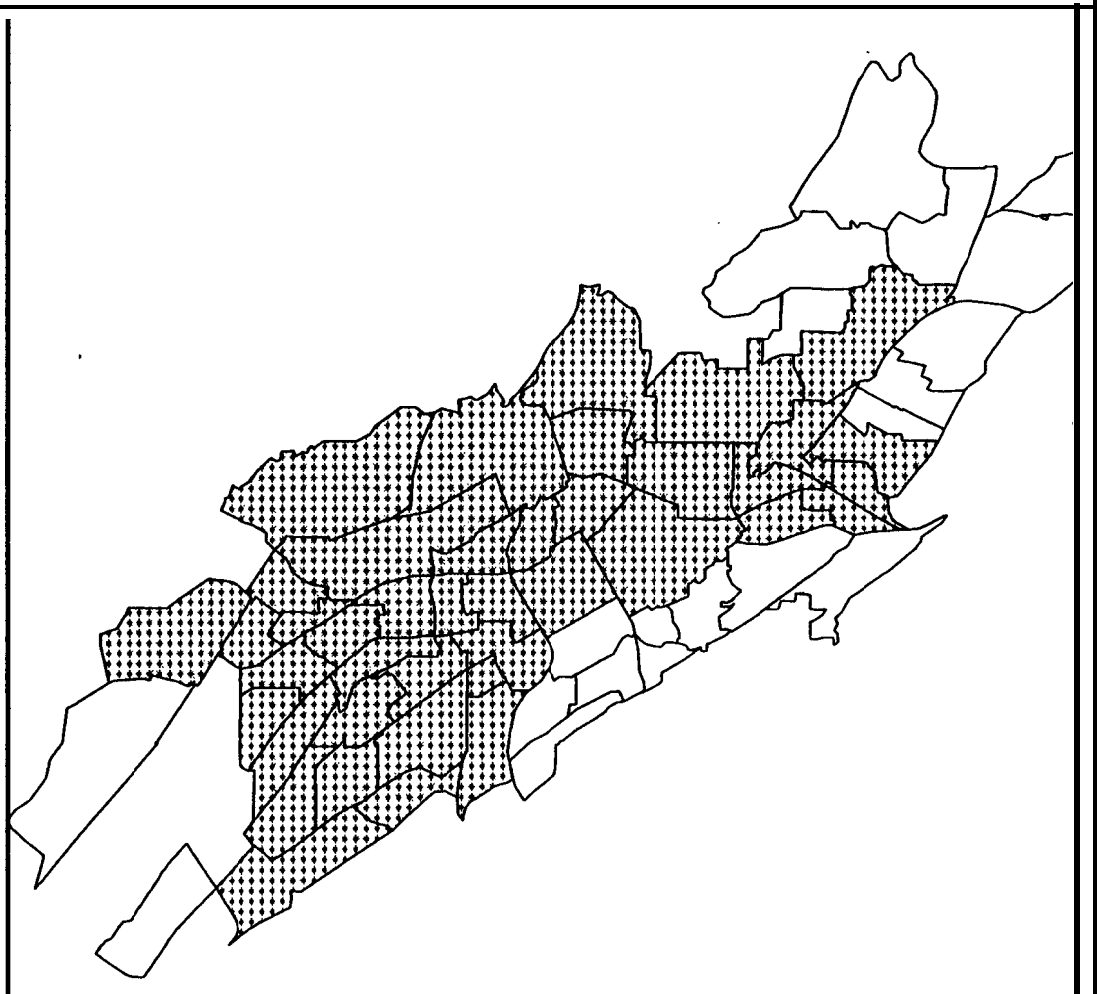
Definitions provided in Table B-1

FIGURE 2

BIRMINGHAM



ALABAMA



Participation in Healthy Start by Census Tract

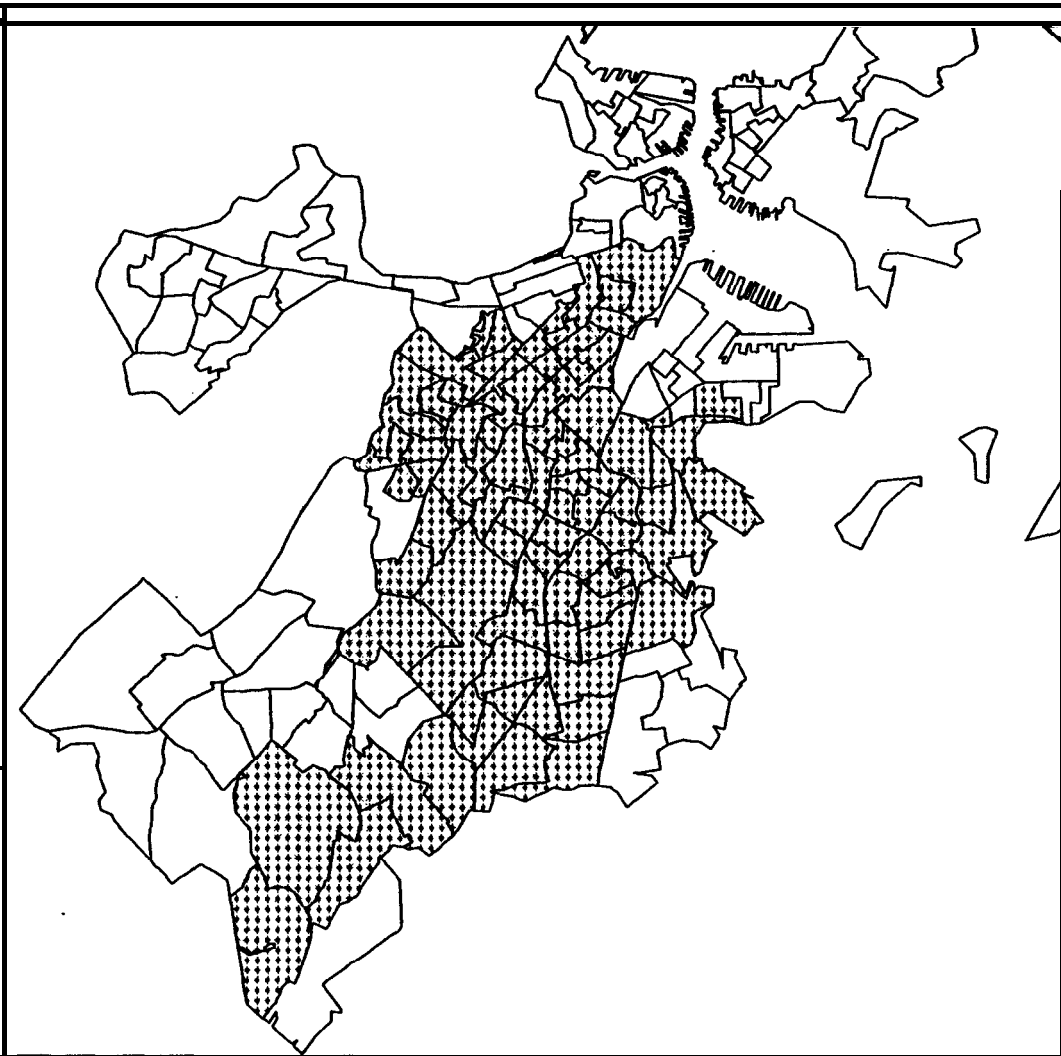
Demonstration Area

Definitions provided in Table B-1

FIGURE 3

BOSTON

MASSACHUSETTS



Particpation in Healthy Start by Census Tract

Demonstration Area

Definitions provided in Table B-1

FIGURE 4
CHICAGO

ILLINOIS

Participation in Healthy Start by Census Tract

Demonstration Area

Definitions provided in Table B-I

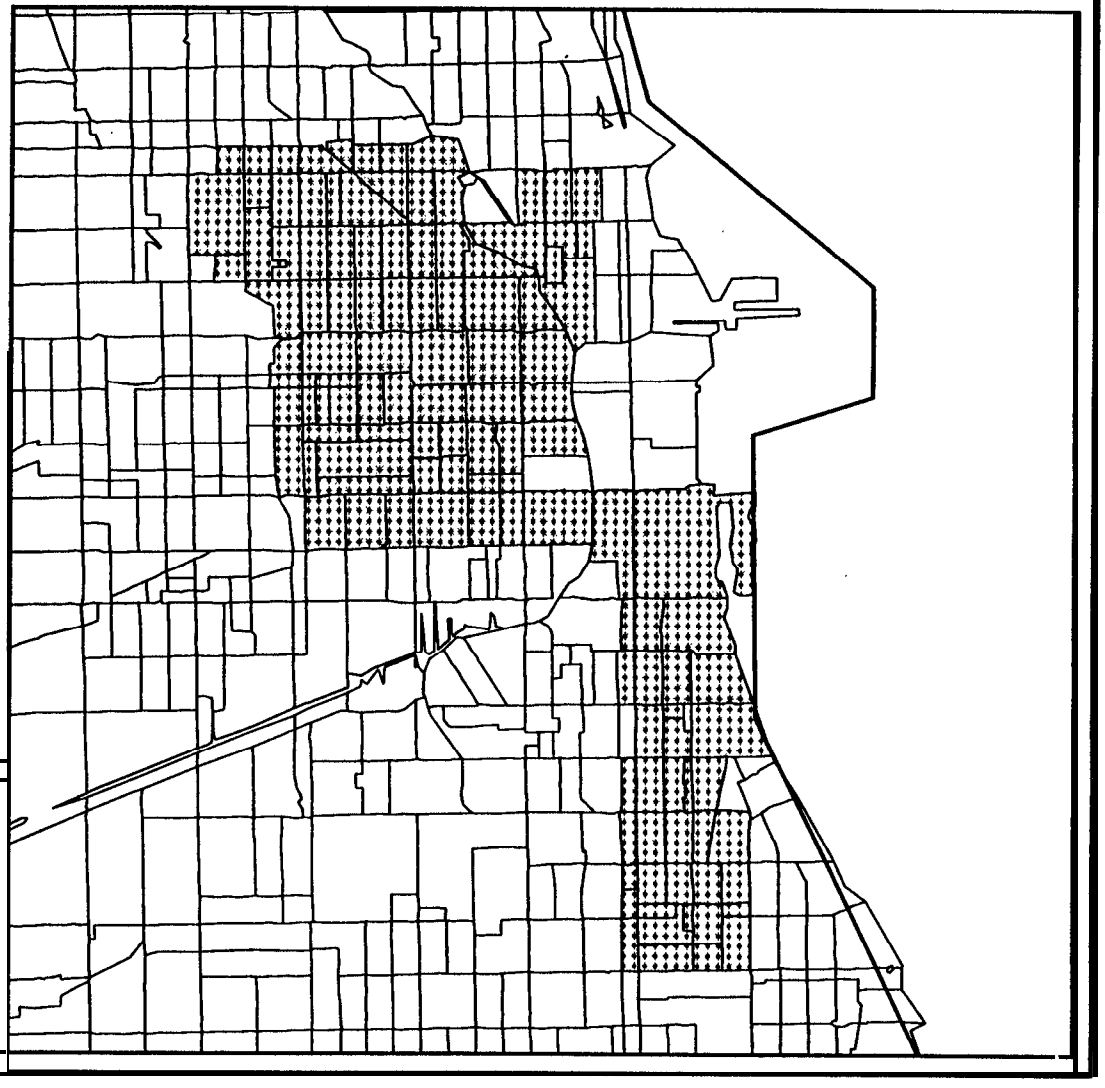


FIGURE 5
CLEVELAND

OHIO

Participation in Healthy Start by Census Tract

Demonstration Area

Definitions provided in Table B-1

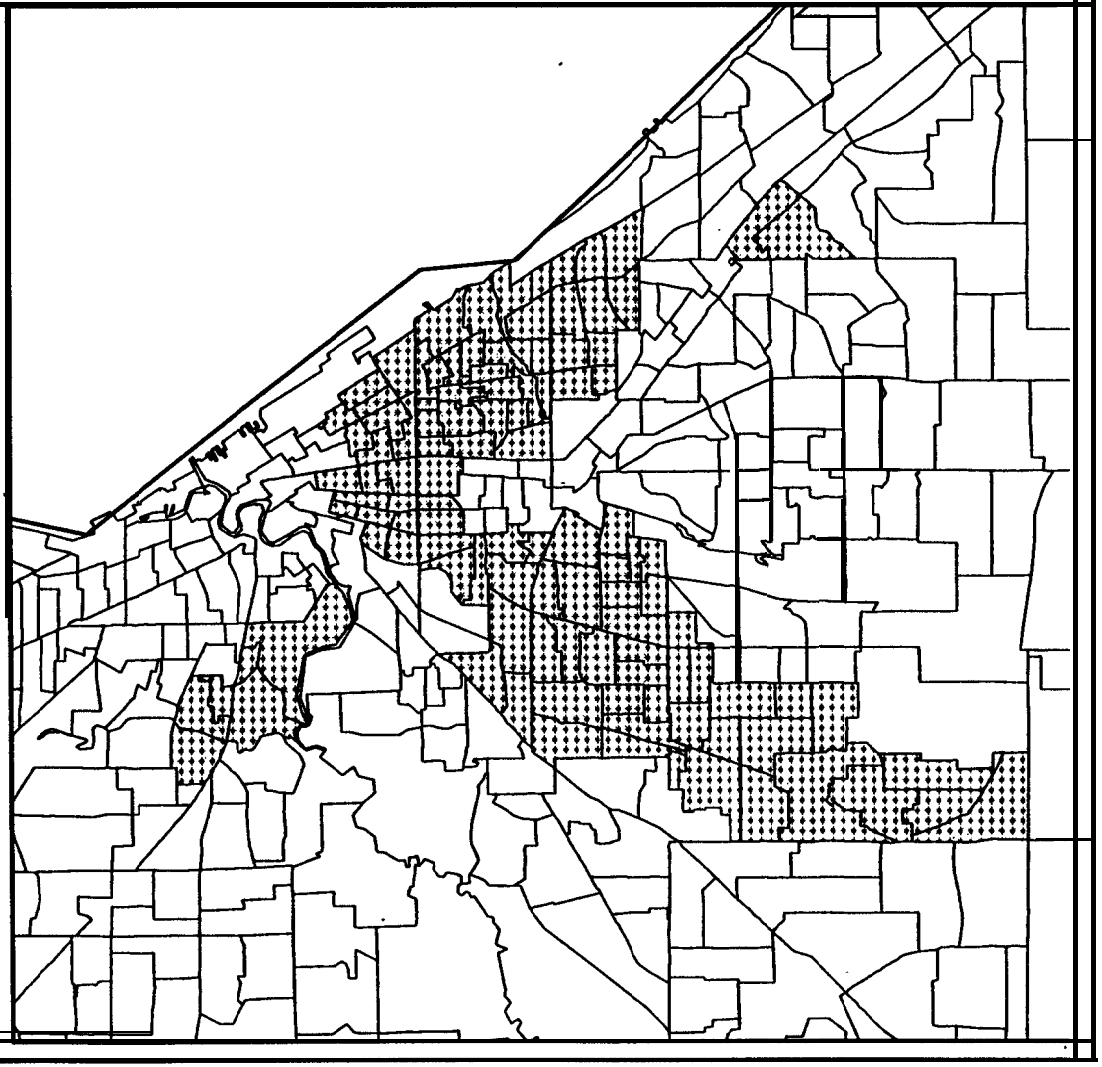


FIGURE 6

DETROIT

MICHIGAN

Participation in Healthy Start by ZIP Code

Demonstration Area

De provided in Table B-1

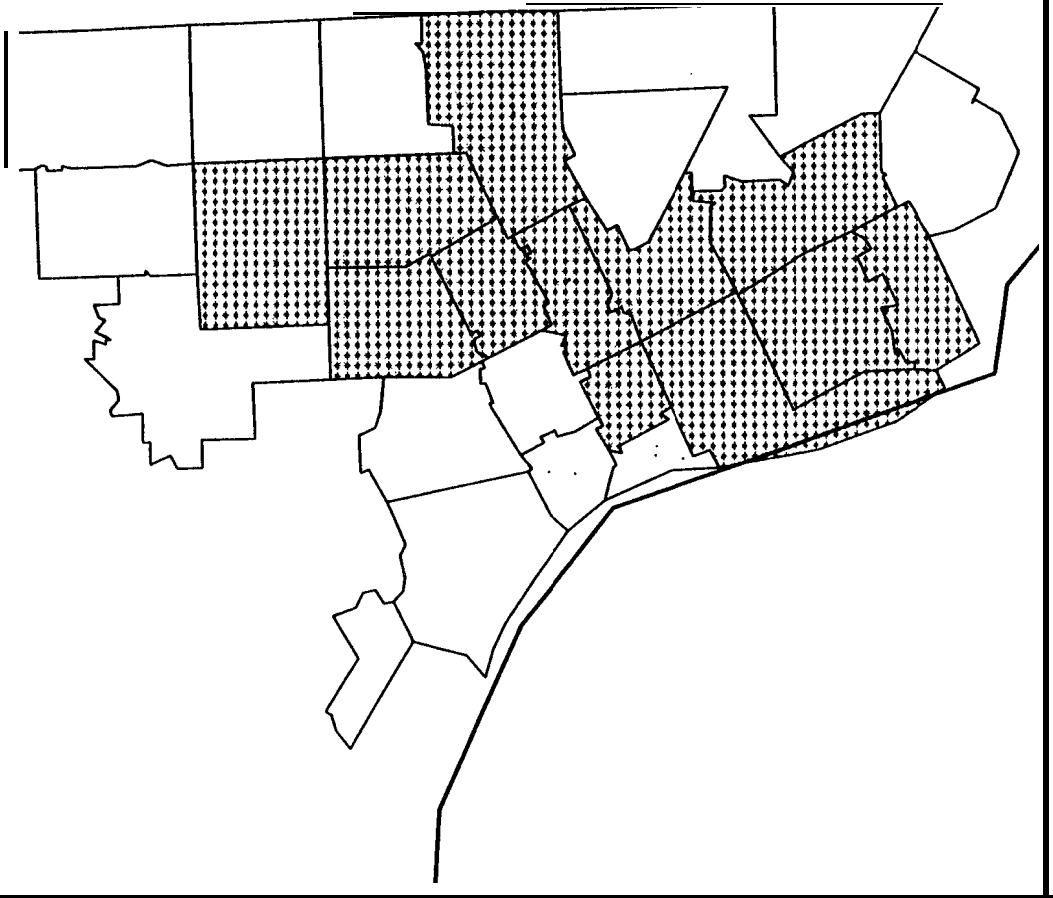
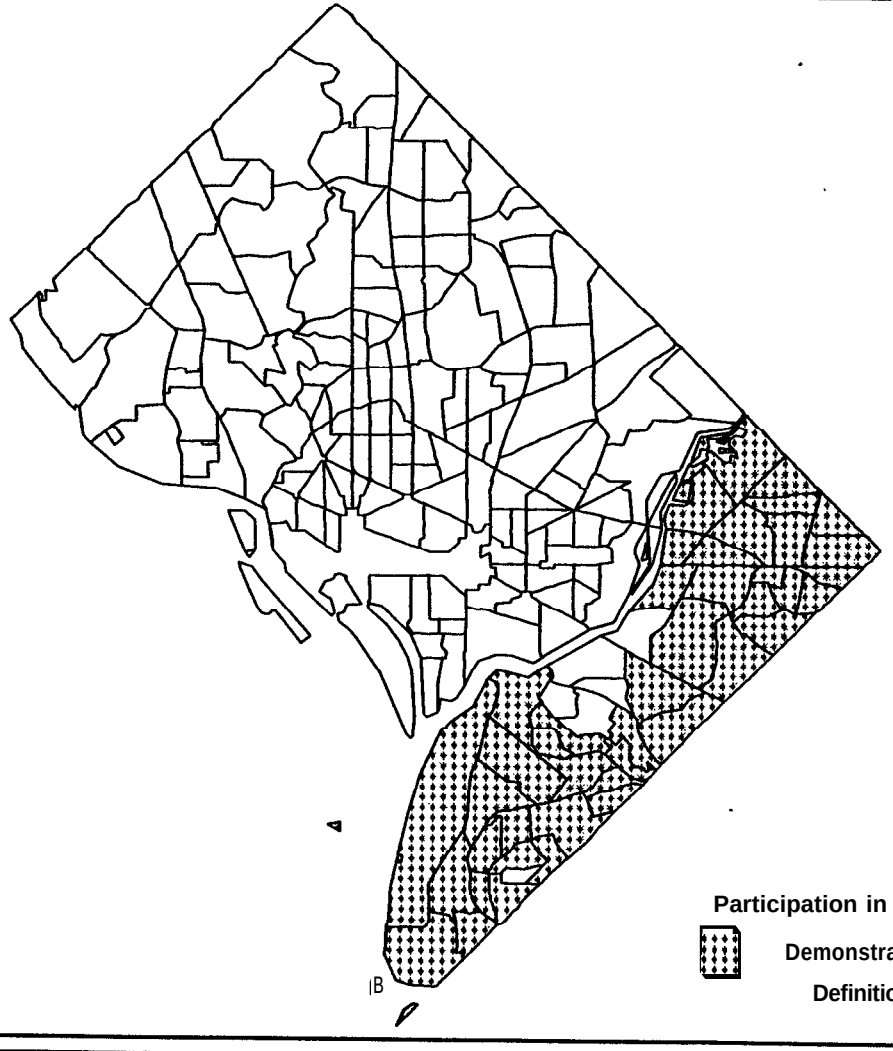


FIGURE 7

WASHINGTON DC



Participation in Healthy Start by Census Tract

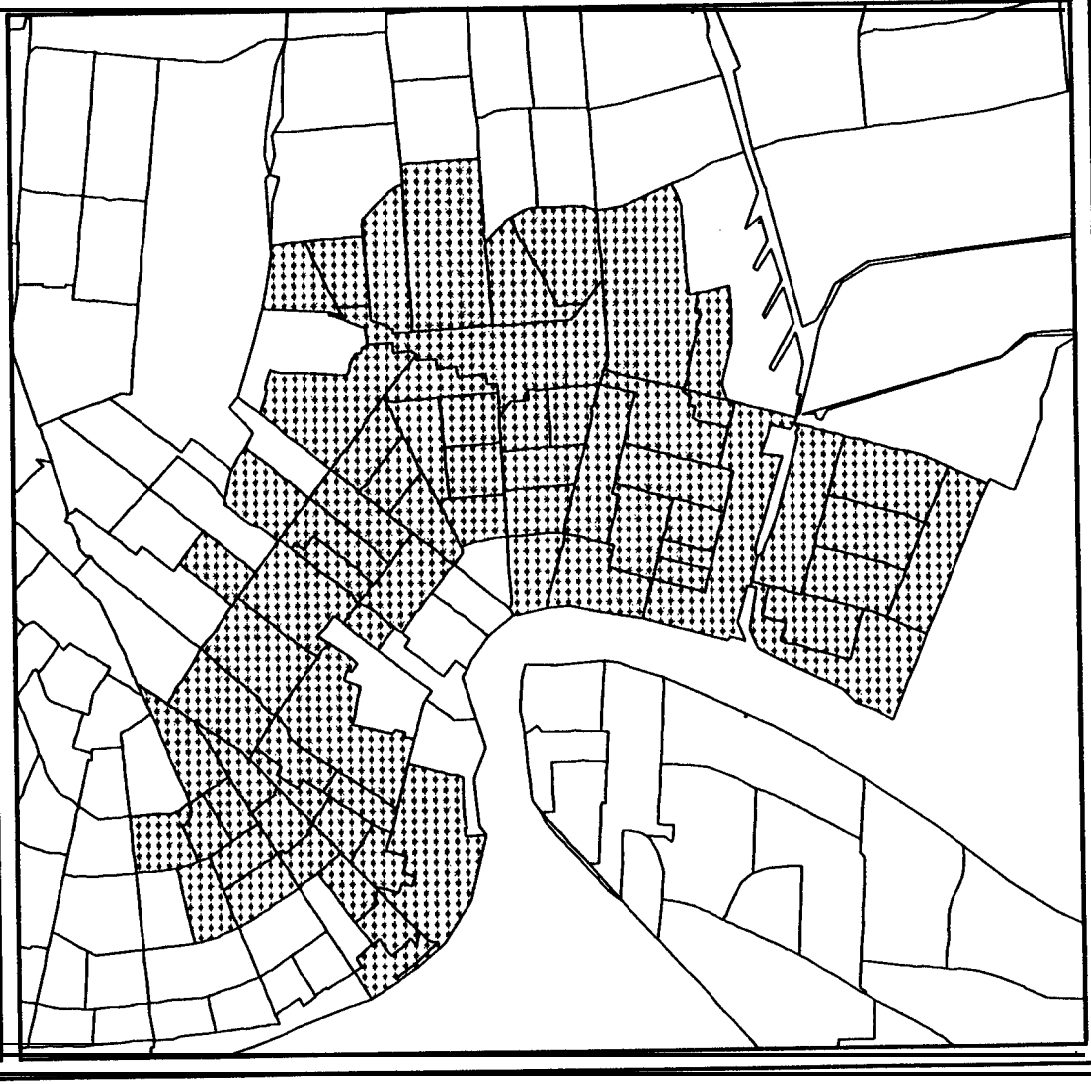
Demonstration Area

Definitions provided in Table B-I

FIGURE 8

NEW ORLEANS

LOUISIANA



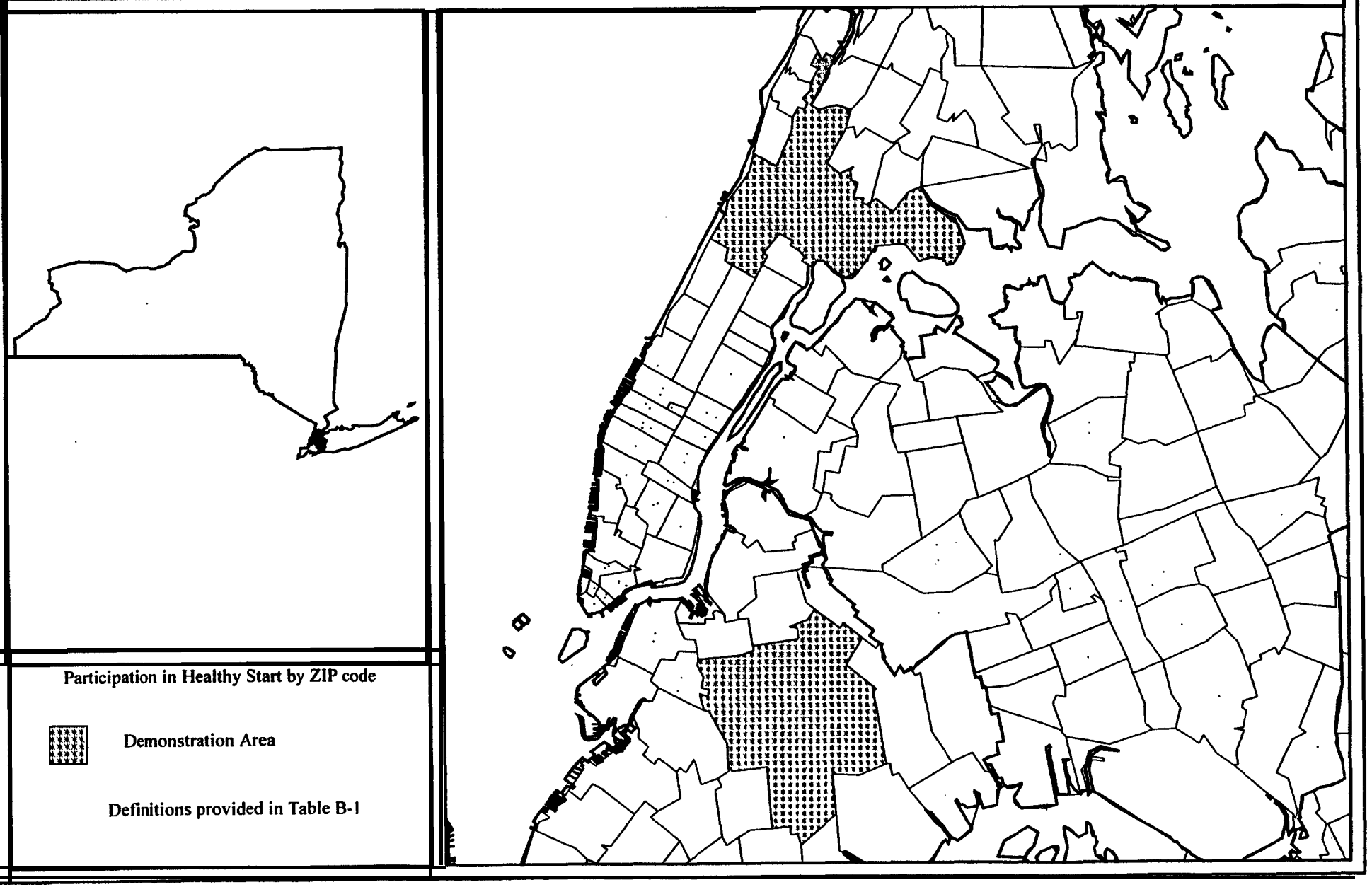
Participation in Healthy Start by Census Tract

Demonstration Area

Definitions provided in Table B-1

FIGURE 9

NEW YORK



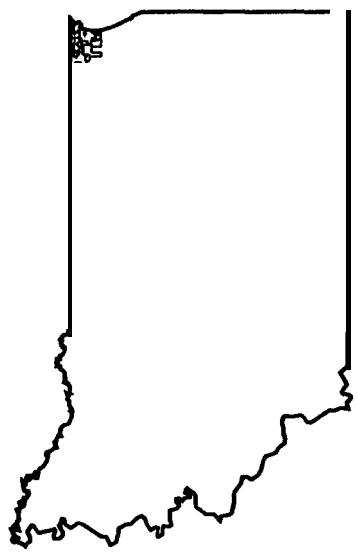
Participation in Healthy Start by ZIP code

Demonstration Area

Definitions provided in Table B-1

FIGURE 10

NORTHWEST INDIANA



INDIANA

Participation in Healthy Start by City

Demonstration Area

Definitions provided in Table B-I

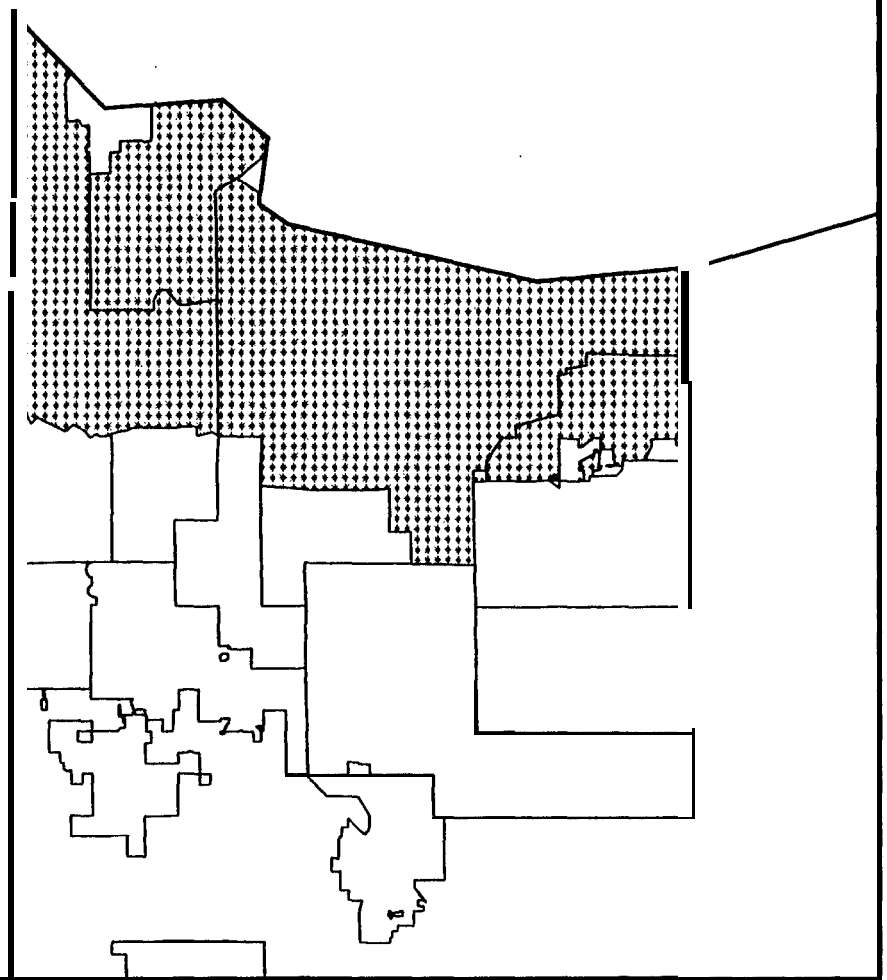


FIGURE 11

OAKLAND

CALIFORNIA

Participation in Health Start by Census Tract

Demonstration Area

Definitions provided in Table B-1

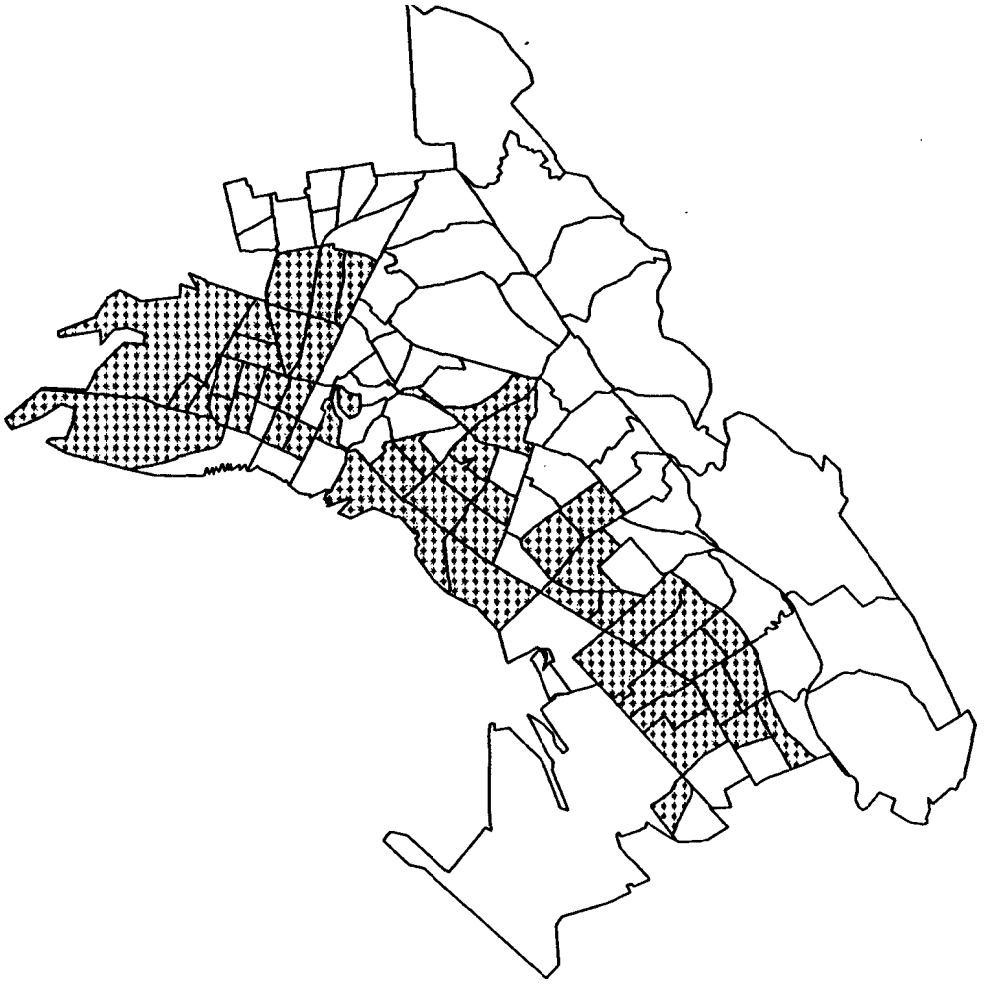


FIGURE 12

PEE DEE, SOUTH CAROLINA

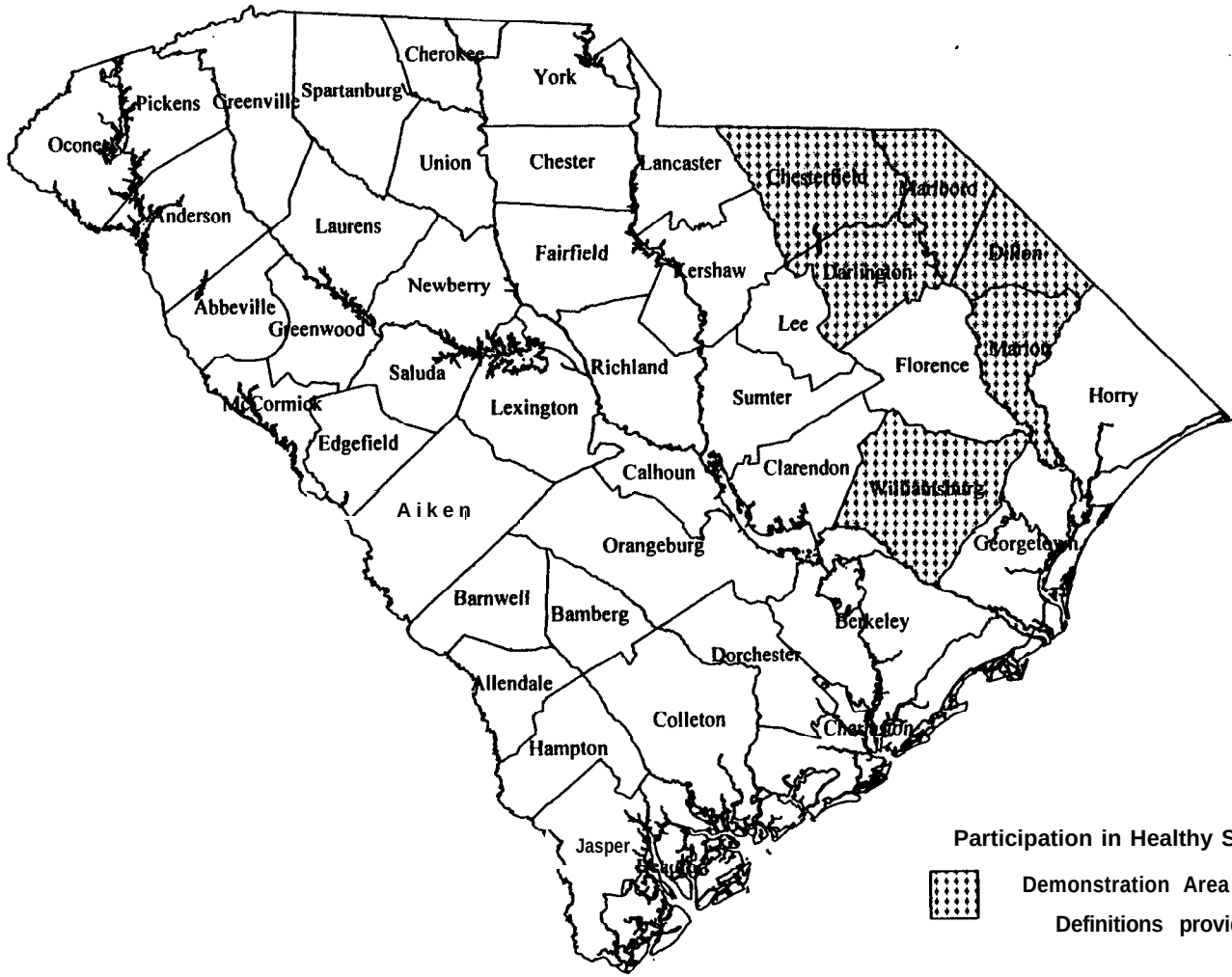
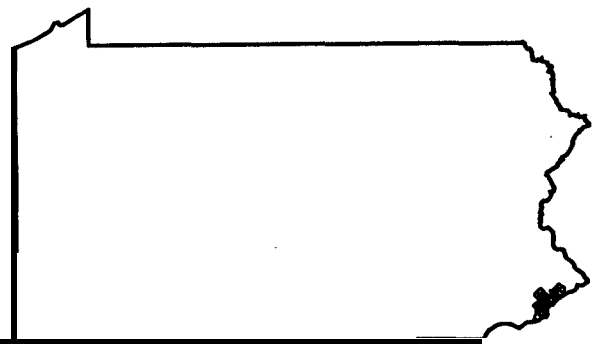
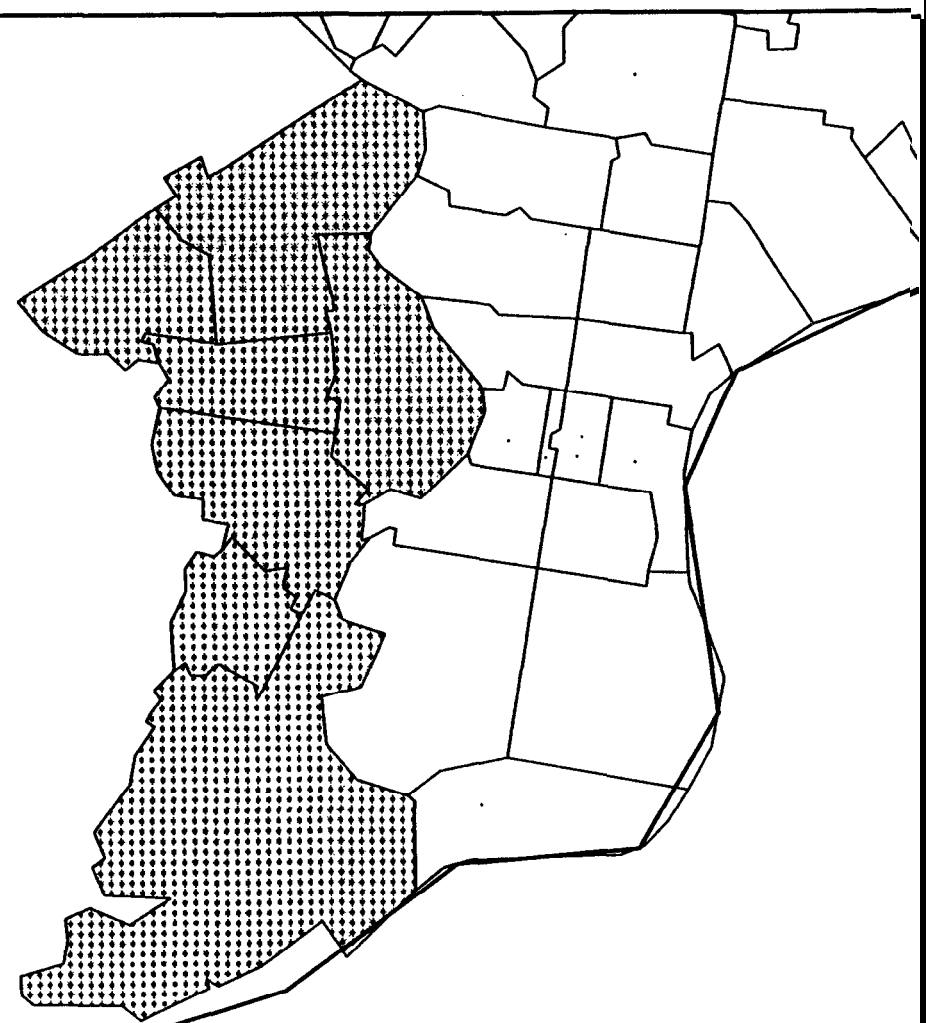


FIGURE 13
PHILADELPHIA



PENNSYLVANIA



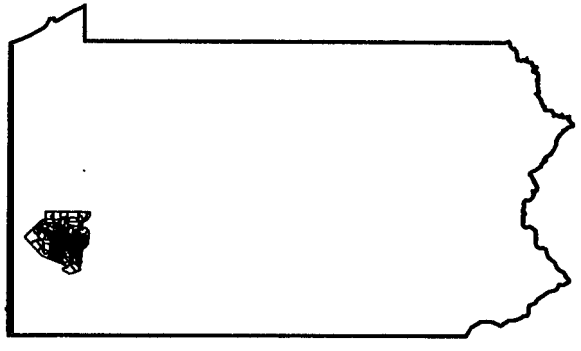
Participation in Healthy Start by ZIP Code

Demonstration Area

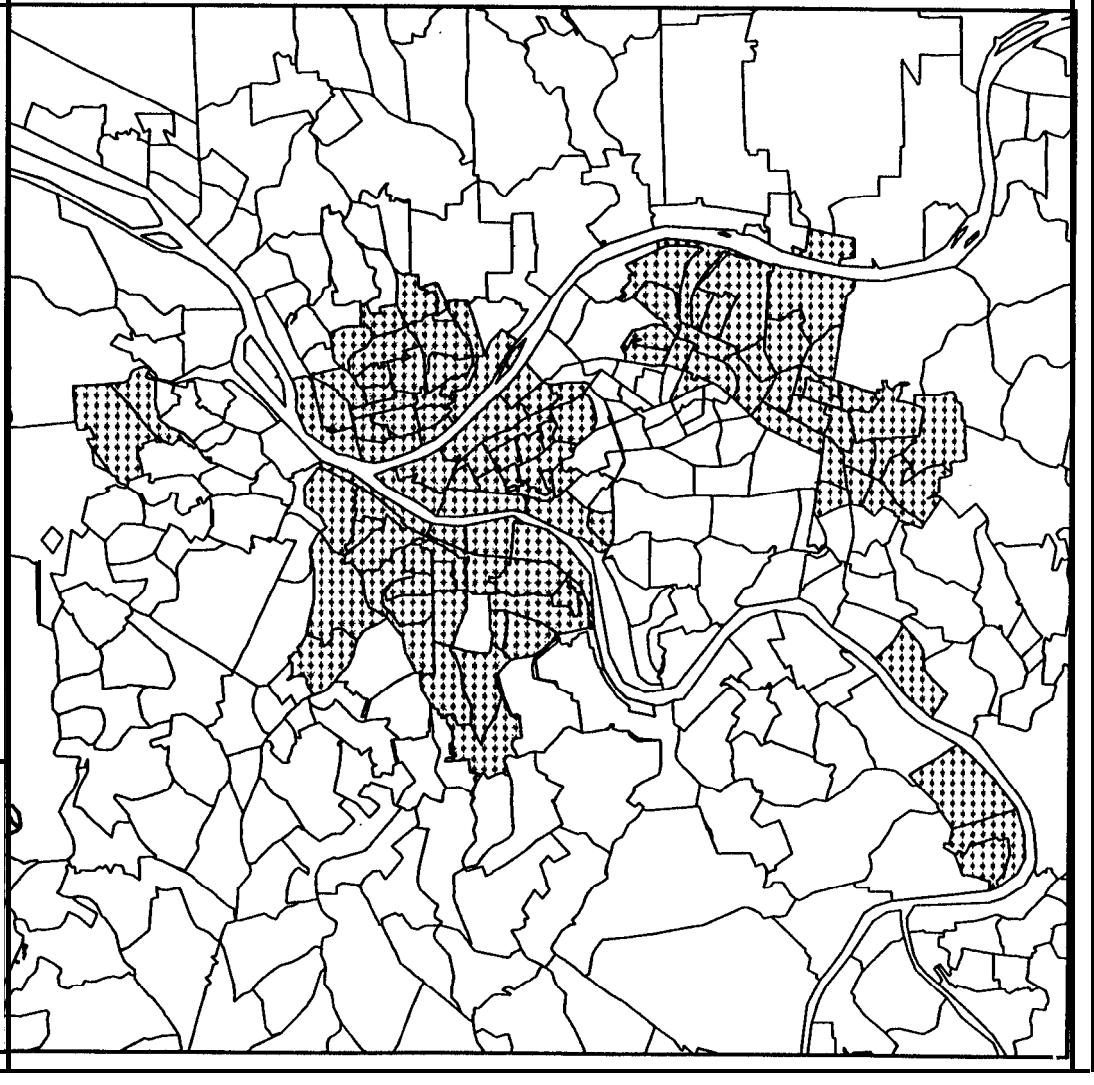
Definitions provided in Table B-l

FIGURE 14

PITTSBURGH/ALLEGHENY COUNTY



PENNSYLVANIA



Participation in Healthy Start by Census Tract

Demonstration Area

Definitions provided in Table B-I

APPENDIX C

FOCUS GROUP BACKGROUND MATERIALS

DESCRIPTION OF FOCUS GROUPS

One component of the National Evaluation's process analysis was a series of focus groups with Healthy Start providers and client participants. The focus groups provided insight into how the projects were being implemented and their strengths and weaknesses as perceived by small groups of project providers and participants. Providers were asked about their roles in the project, how they leamed of Healthy Start, and their perceptions of project successes and problems. Client participants were asked about how they learned about Healthy Start, what prompted them to become involved, how Healthy Start had helped them and how it compared to alternatives available in the community, and how the project could be improved. Both groups also were asked to rate their project's effectiveness in a number of dimensions related to core project goals and activities. Findings from focus groups conducted in 14 of the 15 Healthy Start communities are reported here. Devaney, et al. (1996) reports on results from a series of focus groups conducted in the Northern Plains project area.

In all, a total of 3 1 focus groups were held across the 14 projects: 17 with clients and 14 with providers. As summarized in Table C. 1, input was received from a total of 254 respondents-- 135 clients and 119 providers. Focus group members were selected by local project staff in consultation with the evaluation team. Because there was no attempt to select members randomly, results from the groups cannot be generalized to the full set of project providers and clients. Bather, focus group input provides a glimpse into the lives and circumstances of a small subset of project participants and how they think about the projects. On the whole, the groups were quite candid in conveying their perceptions, and their words provide a "real world" sense of how the projects are impacting Healthy Start communities.

RIVA Market Research, under subcontract to Mathematica Policy Research, conducted the focus groups, assisted by local project staff who arranged for meeting space and refreshments and facilitated transportation for client participants. Project-specific summary reports were prepared by RIVA staff. Our report extracts responses from across all of the focus groups to convey perceptions of Healthy Start as a national program. Individual project nuances are overshadowed by larger trends across the projects. While the text distinguishes between comments from clients and providers, project sites are not distinguished or identified. Common themes and perceptions are presented and illustrated with the participant's actual words.

As shown in Table C. 1, focus group providers collectively represent a wide range of provider types including lay outreach workers, professional social workers and case managers, all types of social services providers, and physicians and other medical care providers. Together, these providers provide a long list of services, shown in Table C.2, representing virtually all the different services Healthy Start projects provide.

TABLE C.1

HEALTHY START NATIONAL EVALUATION
FOCUS GROUP RESPONDENTS

Project Site	Total Respondents: 254 Participants: 135	Providers: 119	Provider Types Represented
Oakland, CA	9	11	Case managers/advocates Family service coordinator/case manager Health educators Infant mortality review staff person Substance abuse counselor Outreach worker/mobile health van driver Life skills coordinator/male program facilitator
Cleveland, OH	8	9	Public assistance program worker Social worker/case manager WIC program staff person Infant mortality review staff persons Outreach/social services program coordinators Physician, medical center coordinator
Washington, DC	9	6	Nurse supervisor, health clinic Physician Outreach and parent education worker Director, research and education program Director, pregnancy prevention program Director, outreach program
Baltimore,MD	12	9	Registered nurse Nurse/case manager Pediatric program clinical manager Social worker/infant mental health specialist Social worker/addiction specialist Case manager Infant mortality review staff/grief counselor Women and teen program staff, multipurpose community center Healthy Start hospital-based liaison
Philadelphia, PA	9	7	Social worker/case manager Program directors (clinic-based child care, telephone hotline) Outreach workers Counselor Housing (health inspector, pest consultant)

Table C.1 (*continued*)

Project Site	**Total** Respondents: 254 Participants: 135	Providers: 119	Provider Types Represented
Detroit, MI	8	9	Social workers/case managers Nurse Public health educator Transportation coordinator Advocate Male outreach worker
Pee Dee Region, SC	16 (4 groups)	16	Coordinators (women's services, family therapy) School nurses Nursing unit manager Teen life center administrator Physician recruiter Day care attendant Bus/van driver Case management team coordinator Office manager Medicaid supervisor Counselor
New Orleans, LA	8	5	Director, teen program Program coordinators (AIDS prevention, WIC) Clinic administrators Dental hygienist
Birmingham, AL	10	6	Early childhood development specialist Health educator Program administrators (pregnant teens, drug treatment, male outreach)
New York, NY	10	6	Substance abuse counselor Social work administrator Outreach/social services staff (housing, advocacy, community relations, teen pregnancy)
Chicago, IL	10	8	Case managers Clinic/social service center coordinators Pediatrician Outreach worker
Northwest IN	8	6	Pregnant teen high school curriculum coordinator Social services liaison Nutrition educator WIC program director Physician/geneticist Substance abuse counselor

Table C. 1 (continued)

Project Site	Total Respondents: 254 Participants: 135	Providers: 119	Provider Types Represented
Pittsburgh, PA	9	12	Transportation coordinator Adult education program coordinator Substance abuse treatment program coordinator Health center child care program coordinator Director, baby supply program Food and nutrition program coordinator Parent education coordinator Case manager Jobs program staff person Advocate/support group provider Healthy Start hospital-based liaison Reproductive health counselor
Boston, MA	9	9	Registered nurse Family nurse coordinator Nurse practitioner Social worker/mentor program coordinator Outreach/health education worker Case manager/advocate Nutrition and health educator Adolescent health educator Peer training program trainer

TABLE C.2

OVERVIEW OF SERVICES PROVIDED BY
HEALTHY START FOCUS GROUP PROVIDER RESPONDENTS

Outreach
Case management
Counseling
Self-esteem building workshops
Mentor and peer-support programs
Advocacy

Genetic screening and counseling
Pregnancy prevention services
Family planning services
Substance abuse counseling and treatment
Substance abuse education
HIV/AIDS counseling and treatment
Environmental health (extermination)

Prenatal and postpartum care
Breast-feeding education and support
Well baby assessments
Immunizations
Health education
Nutrition counseling/education
School muses/school health services
Dental care
Recruitment of medical/clinical providers
Cultural sensitivity training for providers

Fetal and infant mortality reviews
Grief counseling/bereavement counseling

Child care
Therapeutic nursery for drug and alcohol exposed infants
Health care van (mobile)
Transportation to appointments
Translation services
Telephone hotline

Teen centers
Recreational activities for teens
Cultural activities for families
Programs for men: support groups, mentoring programs, outreach

Baby supplies (formula, diapers)
Food pantry/food subsidies
Domestic violence education/support
Parenting classes
Money management training
Literacy training
Job training
GED training/assistance
Job assistance
Housing assistance
Resource referral
Eligibility assistance (WIC, Medicaid)